

Women's Health Action Trust

Annual Report

April 2008 – March 2009

Women's Health Action Trust

Annual Report for the year 1 April 2008 – 31 March 2009

Well Women Empowered in a Healthy World!

Our Vision

Our Vision – embodied in our Mission Statement above - is to ensure that issues related to gender remain on the public health agenda, thereby ensuring women health consumers' needs are recognised, understood and met. We empower 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 families.

We will achieve our Vision by -

- 1) Providing women with information and evidence based resources to enable them to make informed choices and decisions around their own health needs
- 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) 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
- 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

Women's Health Action Trust, which grew out of Fertility Action founded by women's health activist Sandra Coney, is now in its 25th year of operation. This Annual Report covers the period 1 April 2008 to 31 March 2009



Jo Fitzpatrick (Director) Speaking at Gardasil Seminar



Jesse Solomon (Trust Chair) and son Arlo

Chair's Report – Jesse Solomon

This has been my first year in the role of chairperson for Women's Health Action Trust. It continues to be my privilege to work with the lively group of women on the Trust board to support the work of the organisation and staff. In 2008 the trust farewelled Paulette Benton-Greig, the previous chair of the Trust. Paulette provided the Trust with strong guidance during her time as chair and was a committed and valued member of the Trust for a number of years. We have been pleased to welcome some new trustees during the 2008 – 2009 period. Mandy Gregory contributed to the Trust for a period of this year, and Sally Liggins also joined the Trust during this time.

2008 – 2009 has been another busy and successful year for WHA. The staff continue to work at a cracking pace to keep the organisation responsive and productive. It has been a pleasure to see Christy Parker, Policy Analyst and Isis McKay, Office Co-ordinator settle into their roles alongside longer serving staff members. Louise James concluded her time with WHA during this year. Louise developed the Breastfeeding Advocate role substantially during her time with the organisation. It has been a credit to the staff that they have been able to continue and build upon Louise's work in her absence.

Along with a series of successful events and the launch of the new website WHA has continued to perform as advocates for women and consumers in a broad range of areas. I would like to congratulate all the women who contribute to the work of Women's Health Action, and I look forward to another productive and vibrant year to come.

Director's Report – Jo Fitzpatrick

Preparation of an Annual Report is a salutary experience. Every year, the sheer volume of work our small staff gets through amazes me and this year is more astounding than ever. Our new website has delivered beyond our expectations with an average of 90,000 hits per month – something we used to achieve in three months. This has flow-on effects in increased enquiries and orders as site functions allow this. This year we distributed record numbers of our resources. We also use the 'page hits' to inform our priorities for information resources – as they give us 'live' information on what priorities and interests are for our site visitors.

This year World Breastfeeding Week (WBW) was an international gold medal winning event which saw an increase in the number of participants and the number of venues. WBW is a signature event for Women's Health Action Trust and embodies our fundamental principles of community development and empowerment. It is valuable in bringing a whole new generation of young women to the work of our organization.

Over the year, we have done over 40 submissions, consulted and networked with hundreds of others from Ministers and Ministries to NGO's, health professionals, local community groups and individual women. We have distributed record numbers of our resources and spoken at conferences and seminars. This has been a great year for Women's Health Action: the pace has been fast and furious. Women's Health Action continues to meet challenges and to adapt and expand. This is due, in no small measure, to competent, dedicated and enthusiastic staff. Thanks are due to Policy Analyst, Christy Parker, Office Co-ordinator, Isis McKay-Smith and Breastfeeding Advocate, Louise James. We are also blessed with steady governance and a great team of Trustees.

A Snapshot of our Work during the 2008-2009 Year

Women and Consumers: Information and Communication



Women and Consumers: Information and Communication

<p>WHA provided information and assistance to individual women and health service providers</p>	<p>We responded to almost 970 phone calls, 1080 fax and email enquiries and a number of personal calls during the year from individuals, health professionals, students and women’s groups.</p>
<p>WHA published and distributed a regular newsletter and information for individual women, community groups and health professionals on matters affecting women’s health</p>	<p>Over 10,000 Women’s Health Update newsletters were distributed at each publication date during the year – June 08, September 08 , November 08 and February 09 – bringing the annual total distributed close to 50,000. (Copies are available in Appendix 1)</p> <p>During this period, we have also met requests for 20,861 pamphlets and Information Packs. This is a significant increase on previous years and was achieved through an active marketing campaign.</p> <p>We have also developed and updated information on a number of women’s health topics.</p>
<p>Our website www.womens-health.org.nz continues to be a major source of health information both in New Zealand and internationally</p>	<p>Our new website was launched in September 2008. Monthly hits from September to December averaged 74,000 but this increased to an average of 106,000 in the period from January to April. Users cover a wide range of domains including government, organizations and individuals both nationally and internationally.</p>
<p>WHA ran a programme of seminars and events</p>	<p>We organised the NZ World Breastfeeding Week celebrations which saw 1190 mothers and 1217 children participating in the big “latch on” Friday 1st of August 2008 setting a new record with 1122 mothers simultaneously breastfeeding nationwide.</p> <p>We were also awarded an international Gold Medal for participation from the World Alliance of Breastfeeding Action (WABA). Our seminars include two ‘Managing menopause’ educational seminars in May 2008 and November 2008 , our always popular annual Cartwright Lunch (August) and Suffrage Day Breakfast (September)</p>
<p>WHA continues to be active in the community running stalls and doing presentations at seminars and conferences</p>	<p>Parent and Child Show stalls in Auckland and Wellington with La Leche League provide the opportunity to promote our breastfeeding and women’s health messages and resources. Presentations give us the opportunity to stimulate debate, share information and network. Topics this year included health information issues to consumer forums, the health IT community and Library Association conferences; Presentations also to Maternity Nurses’ Study day on consumer views of birth and maternity ; Health and Social Justice conference on women and maternity , Agencies for Nutrition Action conferences on breastfeeding friendly workplaces; . Also National Screening Unit Symposium, Counties Manukau DHB, AUT university; EEO Trust, La Leche League, and Auckland Women’s Centre on a range of topics.,</p>
<p>The WHA database is continuously updated and a major communication resource</p>	<p>To ensure that the WHA database is both current and relevant, we take every opportunity to check it using community directories and available social and health service directories. The database includes over 1000 women’s groups and organisations, around 2500 other organizations and nearly 2000 health care providers including 190 Maori and 75 Pacific health providers.</p>

A Snapshot of our Work during the 2008-2009 Year

Women and Consumers: Policy and Advocacy



Women and Consumers: Policy and Advocacy

<p>WHA represents and advocates, for women health consumers in a number of forums – including seminars and conferences and some international events.</p> <p>Much of our work is ongoing with Working Parties</p>	<p>Women’s Health Action are active members of the Auckland District Council of Social Services, Auckland Coalition against Violence Network, Infant Feeding Association of NZ, UN Convention on the Rights of the Child Working group ,NZ Breastfeeding Authority , La Leche League, Auckland Breastfeeding Assn , Women’s Studies Association, Pacific Women’s Watch and staff attend the EEO Trust awards dinner and the annual International Women’s Day Unifem breakfast. We represent consumers on Organ Donation NZ at regular Advertising Standards reviews and in the Midwifery Review process. (See also our work with Government) We also work with health professional organizations – particularly in midwifery and primary care.</p>
<p>Submissions make up much of our policy and advocacy work. They give us the opportunity to put evidence based information and consumer perspectives in front of policy makers.</p>	<p>We did forty submissions over this period including four each to the Ministry of Health, District Health Boards, the National Screening Unit, Pharmac, the Health and Disability Commission and Select Committees. We did three to the Advisory Committee on Assisted Reproductive Technology and two to the Food Standards Authority, the Medical Council and primary care facilities. We also submitted to the National Health Committee, the National Ethics Advisory Committee, Standards NZ and the Auckland University of Technology. Subjects ranged from aspects of breastfeeding to the review of the HDC Act and Code of Rights and aspects of Informed Consent</p>
<p>Much of our work with Government is as consumer representatives on working committee’s. Our submission work (above) also results in follow-up and ongoing work with Government</p>	<p>Within Government and the health service we worked nationally chairing the Ministry of Health/NGO Working Group, as consumer representatives on the HIV Screening in Pregnancy Implementation group, the NSU Consumer Reference Group and the Health Information Standards Organisation (HISO), regionally with DHBs and the Regional Public Health Services meetings and as consumer representative on the Epsom Day Hospital Committee.</p>
<p>When an issue is of national importance, or if we are approached by the media, we comment for the media - print, radio and television.</p> <p>We also get extensive media coverage during World Breastfeeding Week</p>	<p>Ten issues made the media this year. We did multiple comment and releases on Herceptin, Abortion and Gardasil. We also commented on the naming of health providers by the Health and Disability Commissioner, on maternity and autonomy, on cosmetic surgery, breast cancer, CSL biotherapies and fertility treatment insurance. Christy appeared on national television commenting on PMS buddy – a text alert system for women and their partners!</p>
<p>Consultations, Conferences and seminars</p>	<p>Over the year we consulted with more than 50 different groups and organizations – from central government to local Government. NGO consultations are extensive as we work alongside others on issues and include national groups such as the National Council of Women, the Maori Women’s Welfare League, Family Planning and the National Heart Foundation to local groups and coalitions. We also network extensively at conferences and seminars and very often present at these. Topics covered include women’s and reproductive rights, electronic health records, breastfeeding at work and in public, and NGO and voluntary sector issues</p>

Introduction

We are a nationwide women's health consumer and advocacy organisation. There are a number of streams to our work but the two main ones are 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 month.

World Breastfeeding Week is a major annual event in our calendar and has increasing numbers of participants every year. An in depth evaluation of its reach – in terms of participation and media coverage – is an annual student project we do with students from the School of Population Health. This year's forty page report covers participation rates, media coverage and evaluations from the co-ordinators of the 101 venues nationwide.

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. 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.

We are located in Newmarket, Auckland and lease our office premises on the second floor in 27 Gillies Avenue. We also lease a part of our office space to Lynda Williams for Maternity Services Consumer Council.

1. Breastfeeding

1.1 Breastfeeding Advocate

It was with great sadness that Women's Health Action farewelled Louise James, our breastfeeding advocate, at the end of March after five years with the organisation.

Louise has been a valued and valuable member of our Women's Health Action team since joining us in 2003. She has grown in the role and has developed and expanded it in ways which have been innovative and important, and which have made a real difference to breastfeeding in New Zealand. Her networking and advocacy skills ensured that she took every opportunity to promote, protect and support breastfeeding alongside others active in the field.

Louise's achievements are numerous and she excelled in many areas. She built the 'Big Latch On' into a nationwide event with impressive depth and coverage and ensured that the 'Big Latch On' is an event which is locally owned and driven. It is now established as a significant event on the annual breastfeeding calendar. This was recognized internationally when WABA (the World Alliance for Breastfeeding Action) awarded Women's Health Action a gold medal for participation in 2008.

Louise leaves us with a legacy of excellent breastfeeding images and resources. The CodeWatchers pocket pack and her pamphlets for mothers on 'exclusive breastfeeding' and 'skin-to-skin' are all valuable resources for breastfeeding mothers and the health professionals working alongside them. A series of innovative and challenging posters and the questionnaire - "How supportive are you towards breastfeeding mothers" typify her creative and constructive approach to breastfeeding promotion and support.

Louise made significant inroads and a major contribution to the development of an employer 'Breastfeeding friendly Workplace' certification process. Reducing barriers to breastfeeding on return to employment has been a steady stream of work for Women's Health Action Trust. Louise started by taking the issue to small employers at Rotary meetings and has worked steadily with businesses, HR and Health and Safety managers for a number of years. Late last year and early this year, we were delighted to certify two employers as breastfeeding friendly and the feedback we have had indicates that this makes a real difference to the women working there.

We are delighted to welcome Cathie Walsh to the position of Baby Friendly Workplaces Co-ordinator. WHA breastfeeding work is now supported by a team which includes other staff members and outside contractors.

1.2 World Breastfeeding Week 2008 - Champions of the World!

World Breastfeeding Week occurs early in August each year and Women's Health Action marks the event by organising The Big Latch On. The Big Latch On provides an opportunity for breastfeeding mothers nationwide to get together and simultaneously breastfeed their babies. Once again, World Breastfeeding Week built on previous successes for another record breaking year. This year's Big Latch On was on Friday August 1st and 1193 mothers with their 1220 babies gathered at 101 venues throughout the country gathered at 10am to put their babies to the breast for this record-breaking simultaneous breastfeeding event. We were delighted that 1124 of the mothers were successful so that we broke through the 1000 barrier.

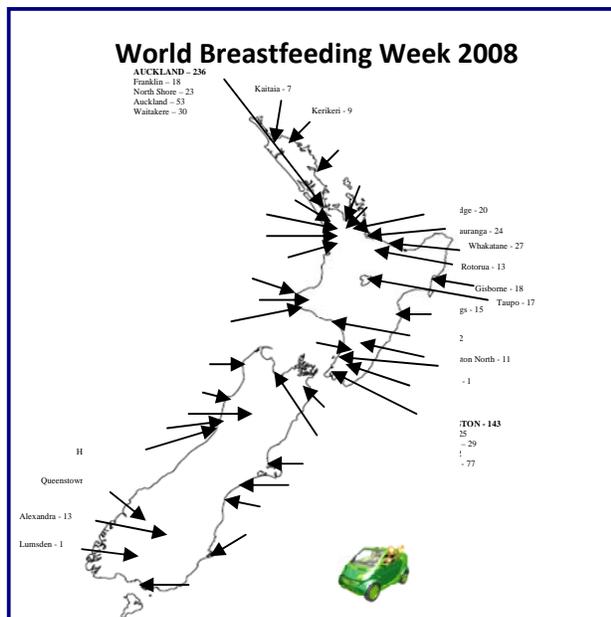
The psychological and actual impact of breaking through the thousand participant barrier by nearly 200 for the official latch-on was satisfying. With nearly 2500 participants nationwide, (an almost 30% increase over last year) this event is making a significant mark on the New Zealand landscape. The co-incidence of the event with the launch of the nationwide social marketing campaign was a useful collaboration which increased the effectiveness of both events. We were extremely proud to be recognized internationally and awarded a gold medal by the World Alliance of Breastfeeding Action (WABA). After the event, the Philippines' organisers 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.

A key media achievement was getting 'Breakfast' to publicise 'The Big Latch On' and the presence of Maori in the group of women that were present on the show.

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. (See Appendix 2 for WBW Promotional Material)



1.3 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.

This year also saw us take great strides ahead in the Breastfeeding friendly workplace stream of work – thanks to a funding opportunity from the Auckland HEHA initiatives.

We were extremely fortunate to be able to progress an auditing and certification process in partnership with key stakeholders and a business partner for ‘Breastfeeding friendly workplace’ certification.

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.

For many years Women’s Health Action has been working at a strategic level to change legislation around breastfeeding provision in the workplace, so it is with much delight that we report that it is now enshrined in law in NZ that employers have to provide for breastfeeding where it is reasonable and practicable. This law will come into effect on the 1st of April 2009. We continue to work with the DOL on the development of a Code of Practice.

Women’s Health Action took advantage of the introduction of the new legislation around breastfeeding provision in workplaces by piloting a Breastfeeding Friendly Workplace Certification process. Progress on this work is covered in separate reports. Major milestones include the development of materials for employer support; the establishment of an independent audit process and the successful accreditation of two employers – GE Money and Vero

Associated outcomes included:

- News item and photo in Employment Today magazine
- Article in Auckland Regional Public Health’s *Workplace Health Newsletter*
- Attendance at EEO Trust Diversity conference
- Presentation at the Auckland Diversity Practitioners Forum
- Distributed 350 Breastfeeding Employer packs
- At the end of the year we set up a comprehensive section on our website for employers, which achieved 500 hits.
- Attendance at Association of University Staff (AUS)’s University of Auckland’s forum on family friendly provisions
- Major consultation with the MOH and Social Marketing campaign team on phase two of their social marketing project around breastfeeding and employment.

1.4 Parent and Child Shows

Women's Health Action Trust advocates for breastfeeding in the community. Since 2005 we have had a stand at the Parent & Child Shows in Auckland, Wellington and Christchurch to promote breastfeeding and distribute La Leche League and Women's Health Action material on breastfeeding and women's health. Women's Health Action manages the stand with volunteers from La Leche League. This year the Ministry of Health and GSL Network also helped staff the stand. GSL Network provided a television and ran the breastfeeding TV ads supported by a large poster on the stand. To enter a draw for an attractive hamper, stand visitors are asked to complete a short questionnaire. This year's question was developed in consultation with GSL Network and asked: *Is your workplace or previous workplace breastfeeding friendly?* With options to tick: no, yes or don't know. 686 people filled out the survey in Wellington - most were pregnant or women with young children.

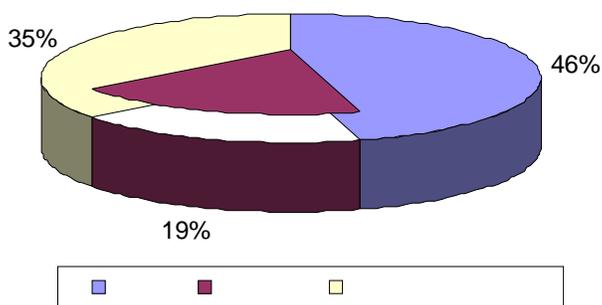


Wellington Stand at the Parent and Child and Show



Stand at the Auckland Parent and Child Show

Workplace Breastfeeding Friendly



The survey revealed a lack of awareness around whether workplaces were breastfeeding friendly or not and a tendency to expect the best from an employer.

A large number ticked the 'yes' box with comments like: "I presume so", "There will be no problem", "I guess so", "It will be, I am the HR Manager", "Assume so", "I hope so", "I don't think anyone would stop me", "I would assume so, I work in a hospital but I haven't seen anyone do it", "I work from home", "It must be it's a hospital" and "I expect they would". For the Parent & Child Show in Auckland the survey question quantified the 'yes' by asking for evidence such as a breastfeeding policy or room. This confirmed our suspicion that most women assumed that their employers would be breastfeeding but had no evidence that this was so.

1.5 Working with the Ministry and HEHA (Healthy Eating; Healthy Action)

Women's Health Action continues to take a consultative and supporting role to the HEHA initiatives at three different levels: strategically with the Ministry of Health in Wellington, regionally with the MOH in Auckland and at a local level with HEHA managers and public health practitioners. Key milestones achieved:

- Powdered Infant Formula (PIF) research published, informing development of information resources around PIF preparation and initiating collaborative work between MOH and NZFSA
- Submission on development of a poster for dissemination of information about the NZ interpretation of the International Code of Marketing of Breast-milk Substitutes.
- The Auckland MOH has funded breastfeeding peer counselor Administrator training.
- ADHB has funded the setting up of a Breastfeeding Hub
- Driven by the Waikato DHB's HEHA team, Westfield now has policy support for breastfeeding in all their malls.

1.6 Other

Breastfeeding as unpaid work

A major initiative to have breastfeeding recognized as unpaid work and to increase data collection was through a submission to Statistics NZ to include one new category in a question for the 2011 Census. We worked with many other NGOs to support our submission. Statistics NZ has included the category suggestion in their write up on the submissions. A decision to include it in the Census is yet to be made

Food security

From our networking and presence at major conferences we discovered a major stream of work on food security was being undertaken by the Wellington School of Medicine. We initiated contact with the researchers and were able to make a substantial contribution, where breastfeeding had been overlooked. The researchers have included the protection of breastfeeding as an element to consider when looking at food security.

Networks

Our breastfeeding networks are comprehensive and extensive. A major stream of work which runs through the year is facilitating the Auckland Breastfeeding Network. During this reporting period the group has become stronger with Maori stakeholders taking a leading role. The meetings are held at Turuki Health Care. We formalised a breastfeeding public health strategy for 2009, taking advantage of other key dates in the public health calendar to publicise breastfeeding. A new subcommittee on World Breastfeeding Week has been formed and the excitement in the group is at a new high. The achievements of 2008 in the Auckland region have been an impetus to do more.

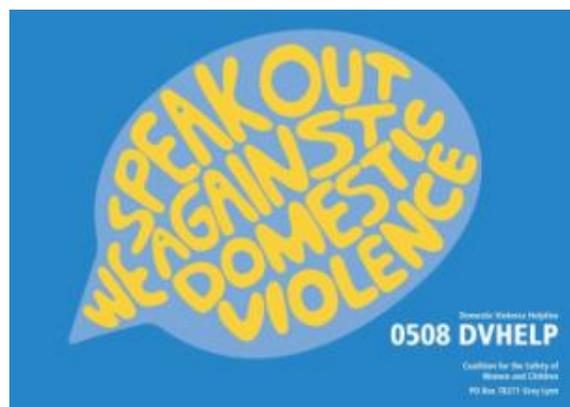
We are represented on the governance board for the New Zealand Breastfeeding Authority. We are the secretariat for the Auckland Breastfeeding Network and Louise James, our breastfeeding advocate is also a founding member of the Infant Feeding Association of New Zealand. We also work with general networks 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. .

2. Women's Health Issues

2.1 Violence Against Women

We continue to view violence against women as a key women's health issue of concern. New Zealand has a high prevalence of intimate partner violence against women. Fanslow and Robinson's 2004 study found 33% of ever-partnered women in Auckland had experienced at least one act of physical and/or sexual violence by an intimate partner. The health consequences of intimate partner violence for women have been well established and include a wide range of physical and mental health effects. We were a founding member of the Auckland Coalition for the Safety of Women and Children which was developed in 2006 to address concerns regarding responses to domestic violence in Auckland. Community agencies met together to discuss domestic violence legislative developments and decided to form a coalition group that met regularly to strategise and work toward achieving the ultimate goal of safety for women and children in Auckland. Members of the Coalition include Auckland Women's Centre, Inner City Women's Group, Preventing Violence in the Home, Supportline Women's Refuge, YWCA, Waiheke Living Without Violence. We have renewed our involvement with the Coalition this year with our Policy Analyst Christy Parker representing Women's Health Action as an active member of the Coalition. Women's Health Action staff participated in one of the coalition's key activities this year coordinating White Ribbon Day (25th November) activities in Auckland. Another key task of the Coalition has been organizing "Behind the Scenes" a DVD competition for young Aucklanders addressing relationship violence against women. Ruth Herbert of the newly established national lobby group Roundtable on Violence Against Women prepared an excellent article for our September 2008 Women's Health Update in which she evaluates how government-led family violence strategies are being actioned.

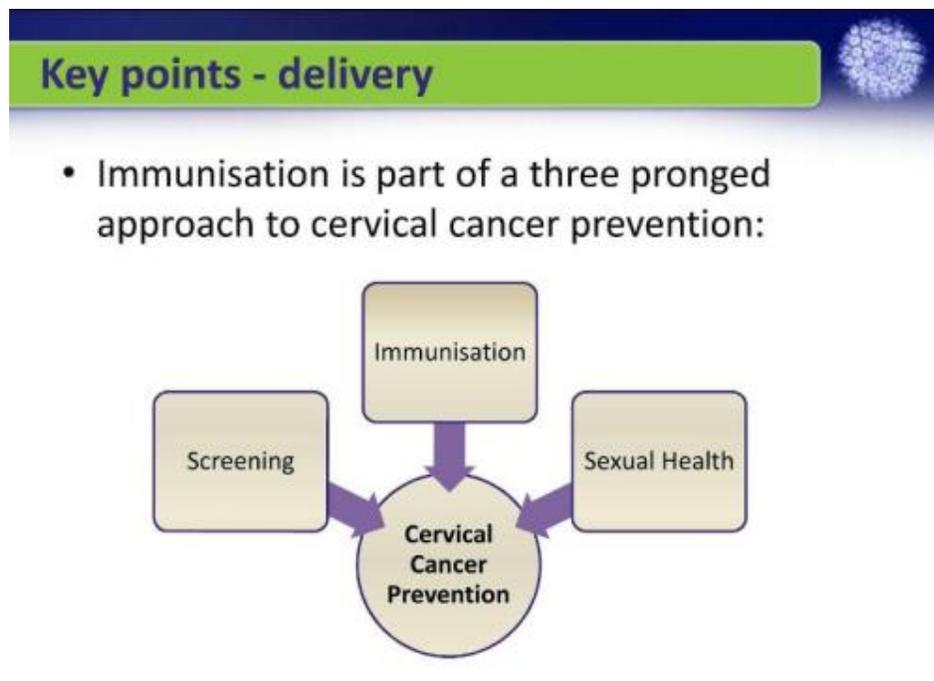
Fanslow, J. Robinson, E. 2004 'Violence against women in New Zealand: prevalence and health consequences', Journal of the New Zealand Medical Association, Vol 117, No 6, November.



2.2 Cervical Cancer Prevention

There have been significant developments in national health policy this year in relation to cervical cancer prevention with the introduction of the HPV vaccine and moves to develop a national sexual health social marketing campaign. Ninety nine percent of cervical cancers are associated with HPV infection, which is largely spread through sexual contact. Women’s Health Action strongly advocates for an integrated “tool kit” approach to cervical cancer prevention in line with World Health Organisation (WHO) recommendations. An integrated approach is one that includes comprehensive sexuality/sexual health education, cervical screening, the vaccine to help prevent HPV transmission, as well as good health and nutrition. The WHO position paper on HPV vaccines states:

HPV vaccines should be introduced as part of a coordinated strategy to prevent cervical cancer and other HPV-related diseases. This strategy should include education about reducing behaviours that increase the risk of acquiring HPV infection, and information about the diagnosis and treatment of precancerous lesions and cancer. Also, the introduction of HPV vaccine should not undermine or divert funding from effective screening programmes for cervical cancer. HPV vaccination is a primary prevention tool and does not eliminate the need for screening later in life, since HPV types other than 16 and 18 cause up to 30% of all cases of cervical cancer. Opportunities to link the introduction of HPV protection vaccine to other programmes targeting young people should be sought (for example, through adolescent health services).



(Immunisation Advisory Centre NZ)

2.2.1 Cervical Cancer Screening

Women's Health Action played a leading role in the establishment of the National Cervical Screening Programme (NCSP) and we have continued to play a role in advising the NCSP through our participation in the National Screening Unit's (NSU) Consumer Reference Group (CRG) as well as through one off consultations with the NSU. We have been active this year in advising the NSU about consumer partnership and participation in cancer screening programmes. We have also been active in advising the National Screening Unit about our concerns at the lack of integration between the HPV Immunisation programme and cervical screening programmes, and the potential of this lack of integration to undermine the life saving success of the cervical screening programme.

2.2.2 Gardasil and the HPV Immunisation Programme

The introduction of Gardasil "the HPV vaccine" in New Zealand and the launch of a national HPV immunization programme has resulted in a major work stream for Women's Health Action. We have held concerns both with the vaccine itself and with the way the HPV immunization programme has been developed. Our concerns with the vaccine include its infancy, the rush to market, the lack of evidence to support its safety/efficacy in young girls, unanswered questions about both the length of immunity and its long term success in preventing cervical cancer. Our concerns about the HPV immunization programme- which is providing the vaccine free to girls 12 – 18 years- include:

- An inadequate and hurried initial planning and development process
- Insufficient level of detail to meet women's HPV information needs and to make an informed choice about the vaccine including an overemphasis on the benefits and de-emphasis of the risks/uncertainties of the vaccine
- The representation of HPV as a women's health issue instead of a community health issue contributing to the gendering of sexual health responsibility
- Overemphasis of the risk of developing cervical cancer to encourage uptake of the vaccine
- Misrepresentation of the action of the vaccine by calling it the "cervical cancer vaccine"
- Failure to integrate with the other key prevention strategies- cervical screening and sexual health education



We have held informed choice seminars, presented conference papers, developed an information pack, written Women's Health Update articles, held meetings with the Ministry of Health and Health and Disability Commissioner, provided advice to the National Screening Unit, and discussed the issue in appropriate media forums.

2.2.3 Sexual Health

In September we attended a national consultation by the Ministry of Health involving sexual and reproductive health workers and related stakeholders about the development of a campaign to focus on improving sexual and reproductive health and reducing inequalities in sexual and reproductive health for 15 to 24 year olds. We were joined by other NGOs including the AIDS Foundation, Family Planning, Auckland Sexual Health Service, Rape Prevention Education and Auckland Sexual Abuse Help. Our November Women's Health Update led with an article "*Let's talk about sex*" *Making a real difference in youth sexual and reproductive health* which looked at the evidence about what works for improving youth sexual health. We are advocating for comprehensive school-based sexuality education and would like to see integration between the school-based HPV immunization programme and school-based sexuality education.

2.3 Eating Disorders Services

The gaps in New Zealand's eating disorders services have been evident for some time with some women being sent to Australia for treatment. This year saw the release of the long and eagerly awaited Ministry of Health report 'Future Directions for Eating Disorders Services'. The report is intended as a road map for addressing the gaps and improving services across all levels from primary, community and prevention strategies and services to tertiary inpatient treatment. The release of the report, and the priority given to eating disorders by the new Government has kick started the regional planning processes for improvements to services.

The national service specifications for mental health services including eating disorders services have already been under review by the Ministry of Health. Women's Health Action submitted on the review of service specifications from a gender-based perspective. We also took on board the concerns we have picked up from calls to the office – which indicate narrow criteria around age and severity of the condition – limit access to services for many. Girls and younger women have much difficulty getting help through current services and all women must reach a serious level of morbidity before they are able to access services.

We have been working closely with the Auckland based EDEN – the Eating Difficulties Education Network - to ensure that the regional planning process includes consultation with community-based NGO's providing prevention and early intervention eating disorders services. This area is so under-resourced that there is a danger that these services – while covered in the national service specifications - will be ignored in favour of primary and clinical services who are consulted during normal planning processes. We are in contact with the Northern District Support Agency responsible for developing a Northern Region Eating Disorders Services Plan, but have found this a frustrating process. Despite the fact that we have no possible pecuniary interest in the allocation of service funding, we were effectively locked out of the consultation process. The planners finally met us once most of the decisions were made and, while this meeting clarified issues for us both, they did not accept a subsequent invitation to meet with the Eating Disorders Community Coalition.

Women's Health Action and EDEN have together re-launched the Eating Difficulties Community Coalition of agencies and individuals concerned with improvements to New Zealand's eating disorders services. The coalition includes Eating Disorders Association NZ, Christchurch's Eating Awareness Team, the Auckland Women's Centre, Auckland Women's Health Council and the Mental Health Foundation. We also provide comment on issues related to women's body image, body size and health, and eating disorders when requested by the media. Our September update article *Community-based NGOs and the future of eating disorders services* looked at the importance of DHB funding for prevention and early intervention eating

difficulties NGOs alongside secondary and tertiary services. WHA staff supported EDEN at their 'Love Your Body' Day event in Aotea Square.

2.4 Abortion Services and Reproductive Rights

Abortion services and reproductive rights have been in the spotlight again this year. We have provided media comments around the Right to Life legal case against the Abortion Supervisory Committee. We have also met with Abortion Law Reform Association to discuss shared strategy and joined their recently created email alert list. We discussed reproductive rights and the need to decriminalise abortion in a National Radio interview. We also had a letter to the editor published in the NZ Herald challenging the push to have all women undergoing abortion forced to view ultrasound scans. In March this year Family Planning announced its intention to apply to the Abortion Supervisory Committee for a license to offer an early medical abortion service in the community. We covered this issue in the Update. Women's Health Action fully supports this move and also issued a press release. Abortion services and reproductive rights is an important and on-going workstream for Women's Health Action.

2.5 Consumer Rights

We continue our work in advocating for consumer rights in health policy and services, and for meaningful models of consumer partnership with, and participation in, health services and planning. We have attended a number of consultations this year where we contribute a consumer rights perspective to decision making. A good example in the current year was the National Screening Unit's national consultation on the retention of newborn metabolic screening blood spot test cards. The three yearly review of Health and Disability Commissioner Act 1994 and the Code of Health and Disability Consumer's Rights fell at the beginning of this year and was a major project. We provided advice to the HDC to assist in the preparation of the Review report and provided a comprehensive written submission. We attended the HDC medical law conference in Wellington and hosted a lunch at Women's Health Action with the current Health and Disability Commissioner Ron Paterson, as well as the Director of Advocacy Judi Strid and Tania Thomas, the Deputy Health and Disability Commissioner and other women's health groups.

We have also been working closely with the HDC and Auckland Women's Health Council on the issue of informed consent and decision making in national immunization programmes, specifically in relation to MeNZB and highlighted with the introduction of Gardasil. We are concerned that the focus of these programmes is high uptake, which is reflected in the marketing strategies and poor quality of information resources, and that this comes at the expense of consumer's rights to make an informed choice about these interventions. We provided a written submission to the HDC on the Commissioner's draft case study on MeNZB complaints outlining our concerns. In response the Commissioner hosted a meeting between ourselves, Auckland Women's Health Council, the Immunisation Advisory Centre, the HDC and representatives from the Ministry of Health including the Director General Steven McKernan, Deputy Director General of Population Health Jancie Wilson and Dr Gerg Simmons, Chief Advisor for Population Health. Women's Health Action presented a briefing paper looking at the evidence about how immunization programme policies affect consumer's ability to make an informed choice in the community. Of key concern for us at the meeting was the issue of where responsibility lies for ensuring that health policy decisions do not undermine consumer rights. The meeting enabled us to present our various perspectives yet little agreement was reached. Follow-up from the meeting has been unsatisfactory and Women's Health Action holds on-going concerns about the fate of consumer rights in population health programmes, in particular those delivering screening and vaccines. Watch this space.

2.6 Health Information and Electronic Health Records

Women's health Action has long been concerned about the use of health information in the health sector and it is an area where we have been involved since the first consultations on health information and personal electronic health records.

The HISAC (Health Information Strategy Advisory Committee) consumer forum was formed in February 2008 because some identified consumer advocates felt the need for a wider reference group. It aimed to provide an opportunity for consumer groups and advocates to come together to advise HISAC on community engagement and consumer issues arising from the use of information in the health care environment. Expressions of interest went out to consumers and their networks – including the Consumer Affairs network; groups who had submitted on health information; and people with a known interest. The consumer forum received the active participation and support from HISAC, the Privacy Commission and the Health and Disability Commissioner.

From the start WHA Director, Jo Fitzpatrick was an active member of the Forum and the position as a leader was cemented by invitations to speak on health information issues and conferences and seminars. She was appointed as the consumer representative on HISAC in October 2008. This was a Ministerial appointment for a year.

HISAC set its vision and direction and believes that the New Zealand health system can be more effective, achieve higher quality health care outcomes, improve patient safety, and reduce error, through the appropriate access and use of personal health information.

Within five years, New Zealanders should enjoy the same degree of confidence with the access to, and use of, their personal health information electronically that they currently enjoy with their banking information.

The Committee will engage with the community and clinicians to advance this agenda.

The Committee acknowledges the foundations laid by the action zones set out in the Health Information Strategy for NZ 2005 and strongly supports the current focus on 'eEvents', such as electronic prescribing, exchange of laboratory ordering and results, and electronic referrals and discharge summaries. These will be universally available by June 2010.

HISAC believes the development of a core summary record of personal health information to be stored and accessed electronically is the next logical development area.

2.7 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 (metastatic) 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. We have also commented extensively on these issues in the media

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. However, this became an election issue and the first action of the new Government was to fund the 12 month treatment for Herceptin. To date, 174 women have opted for this treatment. (Minister of Health press release, (October 2009). About 2300 women are diagnosed with breast cancer each year (NSU website) and an estimated 25% have HER2+ breast cancer which makes about 600 women eligible for the one year treatment of Herceptin. It is interesting that less than one third of them seem to be picking up the opportunity. 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.

2.8 HIV Screening in Pregnancy

A programme proposing that HIV Screening be offered to women in pregnancy has now been rolled out through almost all DHBs in the country. WHA was one of the consumer representatives on the National Antenatal HIV Screening Implementation Advisory Group (NAHSIAG). This Group is administered by the National Screening Unit met quarterly and is now considering whether there is a need for a monitoring committee to replace the Implementation Committee.

We remain concerned about 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.

2.9 Assisted Reproductive Technologies

As Assisted Reproductive Technologies continue to proliferate, so to, do the opportunities and the risks posed by these technologies. The ethical issues raised by some of them are challenging and Women's Health Action continues to provide a consumer rights and women's health perspective on these technologies to help guide decision making. We have provided four major submissions to the Advisory Committee on Assisted Reproductive Technology this year:

- The Use of Frozen Eggs in Fertility Treatment
- Draft guidelines for the Use of Pre-implantation Genetic Diagnosis with Human Leukocyte Antigen Testing
- Consultation on the Use of In Vitro Maturation in Fertility Treatment
- Draft Guidelines on the Use of Donated Eggs in Conjunction with Donated Sperm

We attended the launch of the 'Choosing Genes for Future Children', and the 'Genes, Society and the Future' report launch and seminar. Both these Human Genome Research Project publications are thoughtful and comprehensive. 'Genes and Society' investigates the potential use and regulation of human genome-based technologies in New Zealand, and includes in-depth ethical, legal and public policy

consideration of the issues raised by the rapid advances in genetics. While there are strong debates on ethics and the issues, much of the practice appears to be pragmatic and driven by demand for the technology. We retain strong links with the Bioethics Centre at the University of Otago.

2.10 Media Activity, and Issues of Concern to WHA

We monitor newspapers, magazines, radio and television, and respond to topics related to women's health, and other issues that arise. If it is an issue of primary concern, we will issue a press statement but we also respond to all media enquiries. This year we issued press releases on Herceptin and abortion rights and services. 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 -

- Maternity and autonomy – maternal rights and responsibilities during pregnancy
- The provision of abortion services and the uneven distribution amongst DHBs
- The increasing use of cosmetic surgery and the impotence and reluctance of women whose operations are botched
- The public health implications of Herceptin treatment
- The likely impact on women of insurance provided for women by businesses offering fertility treatment

(See Appendix # 3 for a sample of our media reports)

3. WHA's Information and Education Services

3.1 Information

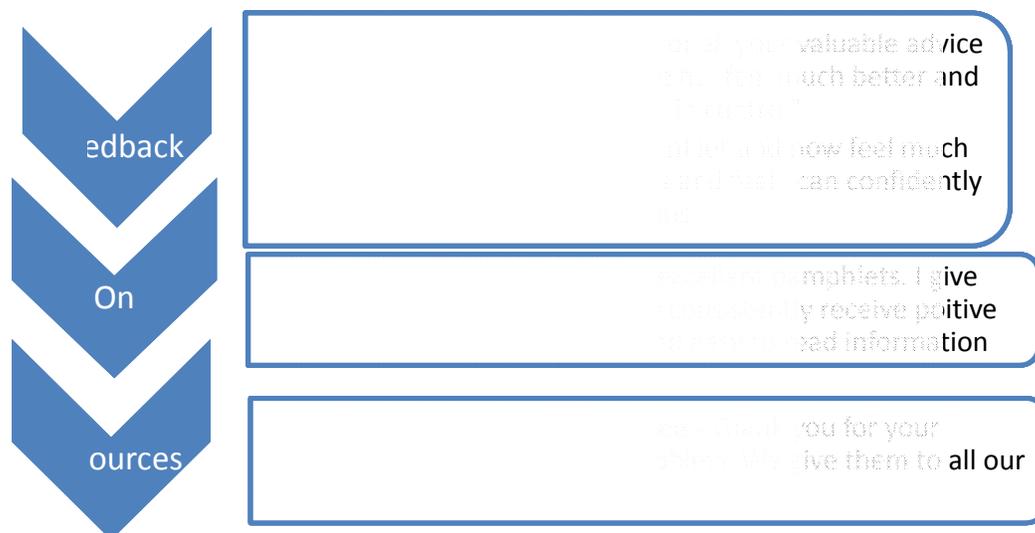
We receive requests for information primarily from individual women health consumers and health professionals. Many come by phone, fax or email, with the occasional letter or a visit in person. Increasingly, the facility on our website is a major source for information requests. We get requests for assistance and researched information from health professionals, academics and other NGOs 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. We have updated 12 of our information packs and have done significant work towards creating a new one on third stage labour. We have also identified the need from the website for a resource on vaginal health. Demand for our resources is increasing exponentially – 14 information packs for this period last year to over 400 this year. This is due to a number of factors – including staff quality and competence; better publicity and promotion and we are delighted with this trend. We hope to maintain and build on it as time goes on.

We have developed and updated a number of our information packs on the following Women's Health Topics

- Caesarian Section
- Hysterectomy
- Bio-Identical or "Natural Hormones
- Phyto-estrogens
- Oral Contraceptives
- Polycystic Ovarian Syndrome
- Pre-Menstrual Syndrome
- Menopause
- Gardasil
- Breastfeeding Friendly workplace – Employers Pack
- Third Stage Labour Pamphlet (Under Development)

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 nearly 21,000 pamphlets and Information Packs). We are consistently receiving positive feedback from consumers, health professionals and other health related organisations on the informative and quality information we provide allowing women to make informed decisions about their health and wellbeing.



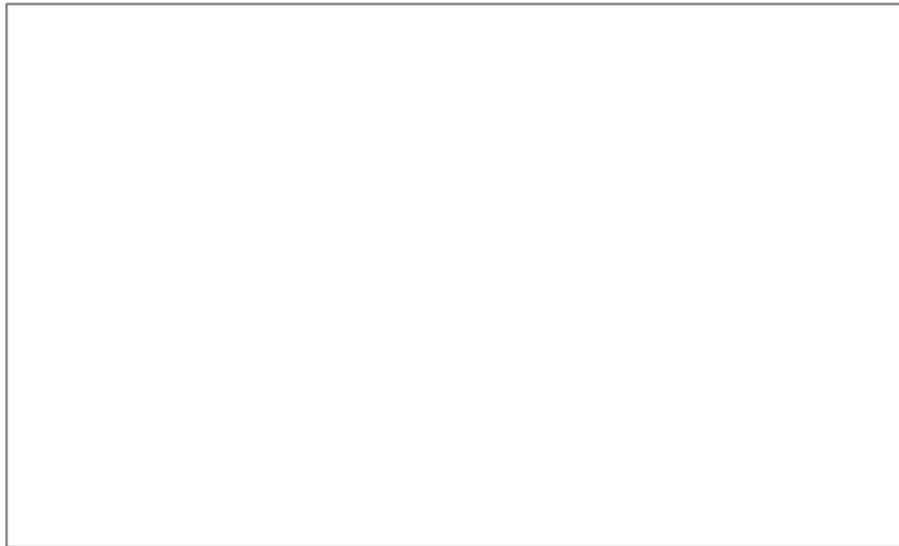
3.2 Website

The website now contains over 300 pages, receives an average of about 100,000 hits every month, and is built on a database structured template which allows us to regularly update it with content which is topical and current. There are at least 350 other sites linking to www.womens-health.org.nz.

The email contact function of our site is working well and has led to an increase in queries from primary health care providers, women's organisations and other health care providers. We also have our resource order form available for download from our site. This allows health professionals and the public to easily order pamphlets, information packs and other resources.

With the ability to easily load new content we have been able to load new research and discussion papers as they become available helping keep the website relevant and topical. Anecdotally we are receiving very positive feedback about this feature of the website – for example following our attendance to symposiums / conferences we source and upload papers and presentations from these events making this information available for a much wider audience.

Commonly accessed pages were Health Topics; Resources and Publications; and Events. The most popular women's health issues were, Vaginal Health followed by HRT, birth control and Depo Provera, Hysterectomy and Abortion and Coming Off HRT. World Breastfeeding Week 2008 was heavily accessed and is always popular over this period. The 2009 World Breastfeeding page has already begun receiving numerous hits.



3.3 Women's Health Update Newsletter

Nearly 50,000 **Women's Health UPDATE'S** were distributed free, courtesy of Ministry of Health funding, to all midwives, practice nurses, Plunket nurses, Family Planning Associations, Maori and Pacific health care providers throughout the country. It is also distributed to the Ministry of Health, DHBs, PHOs in the Auckland and Northland region and other primary care organizations on request. It is also sent to community groups and educational institutions nationwide and to over 5000 individuals. It is included with regular newsletters for the Maori Women's Welfare League, National Council of Women, and the Federation of Country Women's Institutes. health professional service providers and women's groups. 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 June, September and December 2008. Articles during this year included:

- The Maternity Services Consumer Satisfaction Survey 2007
- Breastfeeding – something is happening
- Tackling Family Violence: Turning Strategy into Action
- Community- based NGO's and the Future of Eating Disorders Services
- Latched On and Counted
- Let's talk about sex" Making a real difference In youth sexual and reproductive health.
- The real scandal behind the melamine headlines
- Breastfeeding – friendly workplaces?
- Informed Consent and Immunisation programmes
- Menopause, midlife and metabolism
- Maori women and breastfeeding
- WHA website launch
- Resources and online support group for women with depression

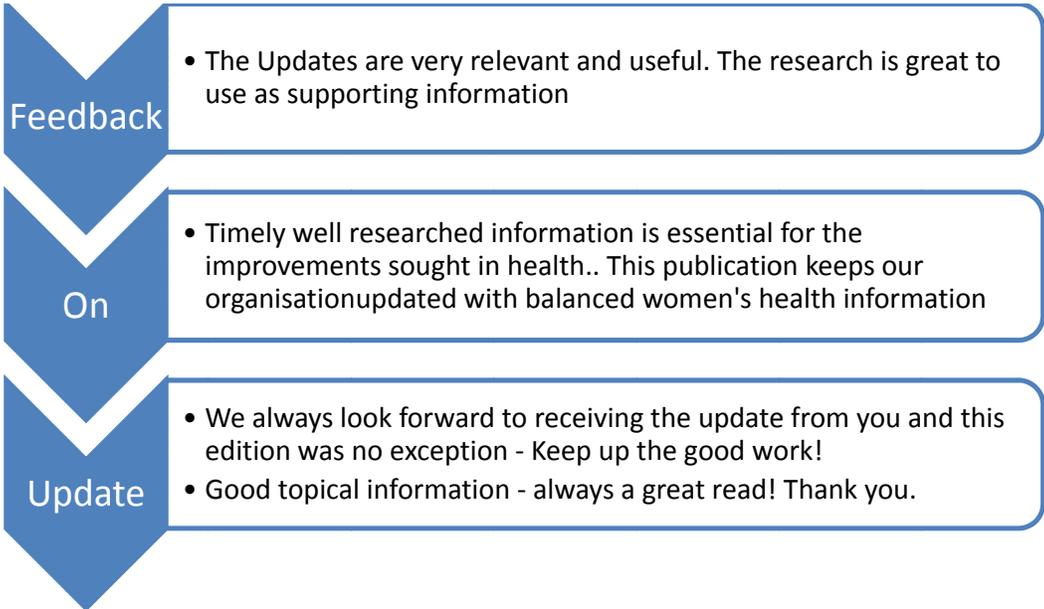
Articles from Update appear on our website www.womens-health.org.nz

We have received positive feedback from the Eating Disorder Sector in relation to the "Community- based NGO's and the Future of Eating Disorders Services" article in our September update, with EDEN and EAT both requesting additional copies of this update to distribute around their networks.

We have received numerous comments and positive feedback on the "Let's Talk About Sex" from people working in the Sexual Health sector also from academics working in this area. We also received positive feedback from consumers and health professionals on the "The real scandal behind the melamine headlines" article.

Feedback from the Informed choice and immunization programmes article was heartening. Many health professionals and providers specifically contacted us to congratulate us on raising the issue – which they felt were long overdue for scrutiny. Consumer feedback was also extensive and positive and resulted in requests for more information, workshops, invitations to participate in research, conferences and lectures; and media interviews. The article has also been referenced in discussions with the Ministry of Health, the Immunisation Advisory Centre and the Health and Disability Commissioner. We have had requests for more information on the studies and resources covered in the newsletter.

We believe that the 25% increase in website hits from February-March can be attributed to the article about the website in the February Update. – *(See Appendix 1 for Copies of the WHA Update)*



women's health update

June 2017

Thirty years of safe legal abortion services

Inside

- The Maternity Services Consumer Satisfaction survey is up
- Breastfeeding – Searching for Support?
- Microboard

Thirty years on from the passage of the Abortion Act in 1967, the Department of Health has published a report on the impact of the Act on the health of women. The report shows that the Act has had a significant impact on the health of women, with a significant increase in the number of women who have had an abortion since 1967. The report also highlights the importance of ensuring that women have access to safe and legal abortion services.

WOMEN ARE THE ABORTION RIGHT!

women's health update

November 2016

Tackling Family Violence: Turning Strategy into Action

Inside

- Community Based HICs and the Future of Domiciliary Services
- Locked On and Locked Out
- Microboard

Family violence is a major public health problem that affects millions of women and children every year. The Department of Health has published a report on the impact of family violence on the health of women and children. The report highlights the need for a multi-agency approach to tackling family violence, involving health, social care, and the police. The report also outlines the Department's strategy for tackling family violence, including the establishment of community-based hubs and the implementation of a national strategy for tackling family violence.

women's health update

May 2017

"Let's talk about sex"

Making a real difference in youth sexual and reproductive health

Inside

- The real agenda behind the maternity headlines
- Breastfeeding: priority or pathway?
- Microboard

The Ministry of Health is in the early stages of planning a large-scale national health awareness campaign to improve the health of young women. The campaign will focus on sexual and reproductive health, and will aim to reduce the number of young women who are sexually active and do not use contraception. The campaign will also aim to reduce the number of young women who are pregnant and do not want to be. The campaign will be implemented through a range of channels, including television, radio, and social media.

women's health update

February 2017

Informed choice and immunisation programmes

Inside

- Maternity, Multiple and Microboards
- Many Women and Breastfeeding
- New Women's Health Action Website
- Responsive and online support group for women

The Department of Health has published a report on the impact of informed choice and immunisation programmes on the health of women. The report highlights the need for a multi-agency approach to tackling family violence, involving health, social care, and the police. The report also outlines the Department's strategy for tackling family violence, including the establishment of community-based hubs and the implementation of a national strategy for tackling family violence.



Panel of Speakers and Sandra Coney - Panel Chair (Exc Lisa Er)

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.

- **Lynda Williams** spoke on Gardasil and the emerging issues to around 50 people at our annual **Cartwright Lunch** held at Ferndale House in Mt Albert on 5 August
- **A political panel of candidates from five major parties standing for election in 2008** entertained over 200 women at this years' Suffrage Breakfast. The panel was ably chaired by Sandra Coney and the debate and contributions were entertaining, informative and lively



Tamaki and Pakaranga College Students enjoying the the 2008 Suffrage Breakfast



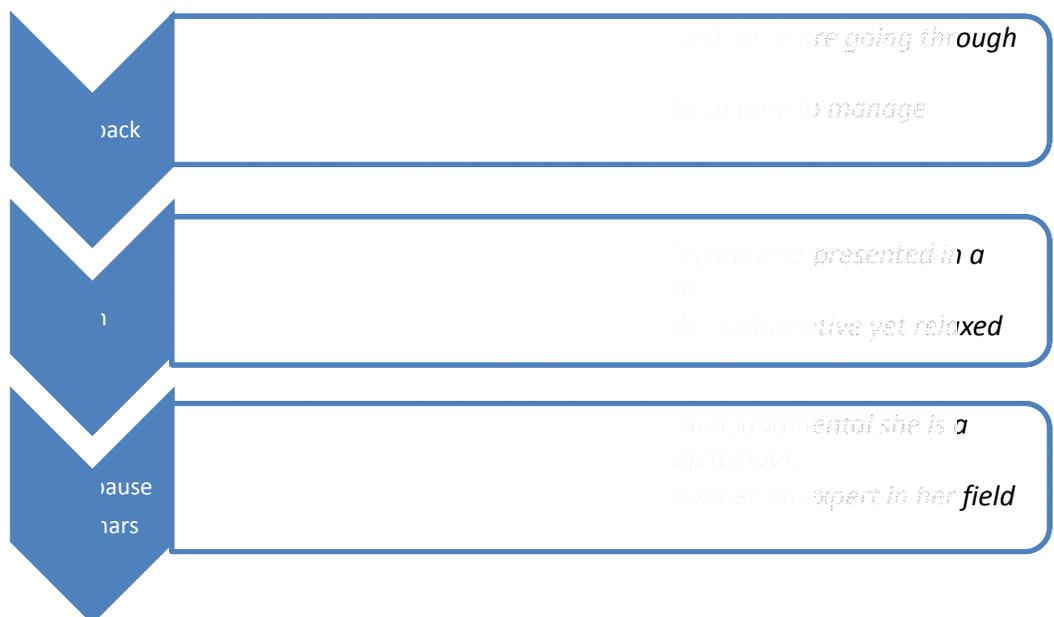
Speakers at the Gardasil seminar

(See Appendix 4 for event promotional material)

3.5 WHA Menopause Seminars

WHA has run two menopause seminars each year for more than ten years – known as the Spring and Autumn workshops. However, this year owing to increased demand, we ran a third. As the demand is growing for these seminars, and evaluations received indicate a preference for small intimate groups, increasing the frequency of the workshops may become a future trend. 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. Evaluations received were all positive.



4. Consumer Representation & Networking

4.1 Policy Analysis, Discussions and Advice

We completed 40 submissions throughout the year – the details of which are :

Ministry of Health

- Antenatal HIV Screening Programme – Quality Standards – May 2008
- National Strategic Plan of Action for Breastfeeding – May 2008
- Mental Health and Alcohol and Other Drug Specialist Services Tier One (Draft Six) and Tier Three – Eating Disorder Services – Service Specification (Draft Six) – *October 2008*
- Feedback to Barbara Hegan on Breastfeeding Poster - *November 2008*

Ministry of Justice

- Improvements to Sexual Violence Legislation in New Zealand - Public Discussion Document – *October 2008*

District Health Boards

- Breastfeeding Action Plan (ADHB) – May 2008
- Primary Health Care Plan for Auckland City 2008 – 2020 (ADHB) – *September 2008*
- The delivery of community laboratory services in the greater Auckland area – (CMDHB) *November 2008*
- Review of National Women;s Health breastfeeding policy(ADHB) – *February 2009*

ACART

- Pre-implantation Genetic Diagnosis with Human Leukocyte Antigen Testing – *September 2008*
- The use of Frozen Eggs in Fertility Treatment – *September 2008*
- Consultation on the use of In Vitro maturation in fertility treatment – *March 2009*
- Draft guidelines on the use of donated eggs in conjunction with donated sperm – *March 2009*

National Ethics Advisory Committee

- Ethics of Intervention Studies – *July 2008*

National Health Committee

- Application of Living Cell Technologies To Conduct a Trail of Pig Cell Transplantation in 8 patients with Type 1 Diabetes – *July 2008*

Justice and Electoral Committee

- Convention on the Rights of Persons with Disabilities – *July 2008*

National Screening unit

- Options for the Consumer Reference Group and consumer participation in screening – June 2008
- Ordering Antenatal HIV Tests – Discussion Paper – *August 2008*
- Draft Policy Options on the Secondary Use and Retention of Newborn Metabolic Screening Programme Blood Spot Cards – *October 2008*
- Ethical and Social considerations in screening Discussion Document– *February 2009*

Medical Council of New Zealand

- Draft statement on advertising for doctors – *February 2009*
- Draft resource on the best health outcomes for Pacific peoples – *March 2009*

Standards New Zealand

- Non-therapeutic use of human tissue – *August 2008*

Statistics New Zealand

- 2011 Census Content – *July 2008*

Food Safety Authority NZ

- 2009 New Zealand Total Diet Study – *July 2008*
- Health Promotion and Policy Research Unit
Outcomes of ENHANCE Food Security and Physical Activity Workshops – *November 2008*

PHARMAC

- *Supporting proposal to fully subsidise non-latex condoms* – December 2008
- Review of Guidelines for the Pharmacology and Therapeutics Advisory Committee (PTAC) and its subcommittees – June 2008
- Funding of 12 months treatment with Herceptin for HER2+ early breast cancer – June 2008

PHARMAC Consumer Advisory Committee

- Voluntary Checklist for Health Consumers Organisations Entering into Health Industry Sponsorship – *October 2008*

HDC

- Review of the HDC Act and Code of Rights – *September 2008*
- Informed consent for MeNZ B Case Study – *November 2008*
- Review of the HDC Act and Code – *February 2009*
- MENZ B complaint and response to HDC case study – *March 2009*

New Zealand Breastfeeding Authority

- BFCI Audit tool feedback – May 2008

Select Committees

- On Employment Relations (Breaks and Infant Feeding) Amendment Bill – May 2008

Auckland University of Technology

- Symposium on violence prevention - Early intervention and therapy- *March 2009*

Primary Health care

- Review of breastfeeding policy – River Ridge Birth Centre – *February 2009*
- Review of breastfeeding policy – West Fono – *February 2009*

Communication and ongoing follow-up with:

- *The Health and Disability Commissioner's Office following the MENZB case study submission.*
- *EDEN, EAT and regional DHB on Tier Three – Eating Disorder Services – Service Specification (Draft Six)*
- *The Health and Disability Commissioner's Office on the Review of the HDC Act and Code of Rights*
- *The National Screening Unit on Ordering Antenatal HIV Tests – Discussion Paper.*
- *The National Screening Unit on draft policy options on secondary use and retention of newborn metabolic screening programme blood spot cards.*

4.2 Networking with Women's groups and Key Health Agencies

Networking continues to be integral to the work of WHA. The addition to the staff of Isis McKay-Smith as office co-ordinator and Christy Parker as policy analyst has injected new energy into this area. Both are excellent and enthusiastic networkers. Isis uses every opportunity and any 'down' time to actively link with other organisations to familiarize herself with their programmes of activity and areas of interest. She also uses these communications to request current information from them.

Christy brought with her active links with other feminist organisations and has also joined the governance boards of three of our major sister organisations – EDEN; the Auckland Women's Centre and the Auckland Women's Health Council. Both have added substantially to our already extensive and established linkages and collaborations with other agencies. They have also established and re-established active links to ensure information flows are constant, issues based and relevant.

Nationally, two of our major networks are the Ministry of Health NGO Working Group and the NZGG Consumer Collaboration – both of which are chaired by WHA Director, Jo Fitzpatrick.

We send out and share information with other NGOs interested in women's health and alert them to issues as they arise which we think will interest them. We initiate collaborative action and have met with the major mental health group – Mental Health Foundation – to look at a collaborative plan of action around gender.

The three yearly review of the HDC Act and Code took place during this year and involved a number of consultations with other NGOs including the Auckland Women's Health Council, Disabled person's Assembly, CCS Disability Action, the Federation of Women's Health Councils, the Centre for Compassion in healthcare and the Privacy Commission. WE have also participated in followup consultations since the review process was completed including a national consultation on the addition of the right to compassion in the Code.

This has been a busy time, particularly for the Women's Sector. For example following a successful Women and the Election Forum in June, we organised with the Auckland Women's Centre a follow-up forum - which was also well attended. We have worked closely with community eating disorder agencies around the country as the role of these organisations in the future of eating disorder services is negotiated. We also worked with the Auckland Women's Centre, Stop Demand and The Mental Health Foundation to review and submit on the improvement to sexual violence legislation. We have continued to send out and share information with many other NGOs interested in women's health, and have alerted them to issues as they have arisen. We have initiated or had ongoing collaboration with a number groups. The groups we are in regular contact with include (but not limited to): Cervical Screening programme - Consumer Reference Group, The National Screening Unit, Federation of Women's Health Councils, Hapai te Hauora, women's centre's nationwide, Maternity Services Consumer Council, WONS: Nursing, Education and Health Promotion Service; Agencies for Nutrition Action, National Heart Foundation, NZ Cancer Society, Alcohol Healthwatch, ASH, Health Promotion Forum, Public Health Association, The Mental Health Association, Action on Smoking and Health, Stop Demand and the Auckland Womens Health Council. WHA is currently the treasurer for the PHA Auckland branch.

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

- **Consultations with:** EDEN; Health and Disability Commissioner; GSL network on Breastfeeding promotion campaign, WONS; Sexual Abuse Help; Mental Health Foundation; DHBNZ; Hapai te Hauora; Working Women’s Resource Centre; Auckland NGO IT network; National Heart Foundation; Auckland City Community advisor; Stop Demand ; Courage’s Women ; Auckland Women’s Centre
- **Specific Submission and resource related consultations including but not limited to:**
 - EAT and EDEN on – Tier Three Eating Disorder Services
 - Midwives and other maternity providers, and consumers on Third Stage Labour Pamphlet (Under development)
 - Maternal Mental Health Unit – Developing the Mental Health Pages of WHA Website.
 - Sexual Health Service , Gay Help Line- Wellington, “Schools Out” Queer youth groups, Women’s rights officer - Auckland, National Student Association and The Auckland Women’s Centre – on the “Let’s talk about sex” November Update Article
 - Maternity Services Consumer Council – Online Submission on Auckland Based Laboratories
 - Mental Health Foundation – Gender and Mental Health Literature review and research proposal.
 - HDC, Disabled Persons Assembly, CCS Disability Action, and The Privacy Commission – On HDC Review of the Act and Code.
 - EDEN, EAT and Jenny Carryer (Professor Of Nursing Massey University) on Obesity, Health & Gender literature review.

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 is both current, and dynamic and includes all the major consumer and women’s groups in New Zealand. . After every Update mailout, returned mail is reviewed and we use several published lists to ensure it is current . This year these have included, but are not limited to:

- Directory of Support Services - Raeburn House
- The New Zealand College of Midwives Database
- Everybody.co.nz
- TAKOA Te Aka Kumara o Aotearoa
- CommunityNET Aotearoa
- Women’s Refuge

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.

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
- Auckland Women's Health Council
- Auckland Women's Centre
- Eating Difficulties Education Network (EDEN)
- Action for Children and Youth Aotearoa (2007 –
- Organ Donation NZ (2007 -) Ongoing)
- HISO, Security and Authentication Committee (2007 -)
- Auckland Cervical Screening Program.

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
- Isis Mckay – Smith Office Coordinator
- Christy Parker Policy Analyst

Trustees

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

- Paulette Benton-Greig Chairperson
- Jesse Solomon Secretary
- Jenny Kirk Treasurer
- Lydia Sosene
- Catherine Crooks
- Mandy Gregory
- Sally Liggins

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.

Women's Health Action Staff and Trustees



Clockwise from top left - Christy Parker (Policy Analyst), Louise James (Breastfeeding Advocate,) Isis Mckay (Office Coordinator), Linda Mckay (Financial Controller), Catherine Crooks (Trustee), Jenny Kirk (Treasurer), Jesse Solomon (Chair – with son Arlo), Jo Fitzpatrick (Director)

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.

Well Women Empowered in a Healthy World !

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*