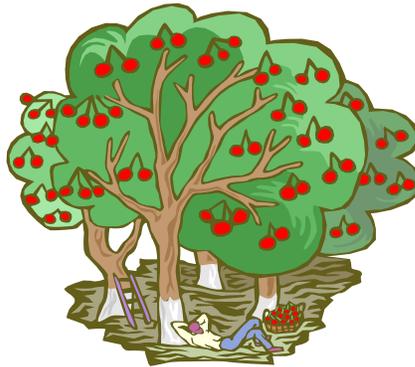




AUCKLAND WOMEN'S HEALTH COUNCIL

NEWSLETTER

MARCH 2015



WHAT'S INSIDE:

- Celebrating the life of Judi Strid
- Patients Harmed in Clinical Trials Not Covered by ACC
- Time to Come Clean on Breast Screening
- Cartwright Conference - Friday 7 August 2015

PO Box 99-614, Newmarket, Auckland. Ph (09) 520-5175

Email: awhc@womenshealthcouncil.org.nz

Website: www.womenshealthcouncil.org.nz

CELEBRATING THE LIFE OF JUDI STRID

On Thursday 26 February 2015 Judi Strid died at home following a four-year battle with cancer. She was 59 years old, the mother of five children and three grandchildren.

Judi was a truly remarkable woman, a leader and one of the most effective change agents in the maternity sector in New Zealand during the 1980's and 1990's. I met Judi in the mid 1980s and we soon became friends and colleagues as we joined and/or established consumer groups and worked on numerous issues of concern in the maternity sector. Judi was an inspiring and hard-working member of the Home Birth movement, Save the Midwives, Maternity Action, as well as many other groups.

In 1986 she helped form and then led the Direct-Entry Midwifery Task Force whose aim was to see the establishment of a direct-entry midwifery programme in New Zealand. Over the next four years Judi led this hugely successful campaign. On 29 November 1987 taskforce members met with Marilyn Waring to discuss strategies for achieving the goal of getting a specialist midwifery training course of a high standard that would be both appropriate to New Zealand and which would also be recognised internationally. As co-ordinator of the Task Force Judi inspired and motivated the rest of us with her passion and enthusiasm for the cause, and over the next few years we vigorously lobbied MPs, wrote letters, applied for funding, produced submissions, networked with other women, researched overseas midwifery training programmes and

attended conferences both in New Zealand and overseas. Without Judi's commitment and countless hours of unpaid work we would not have achieved as much as we did. The passing of the Nurses Amendment Act in August 1990 was an overwhelming victory for all those involved in the campaign.

Few midwives today, and probably not one pregnant woman choosing a midwife to care for her, know just how much they owe to Judi Strid.

The Auckland Women's Health Council was formed in July 1988 following a number of informal meetings about women's health issues held in the early months of that year. Judi was a founding member of the AWHC which became an incorporated society in September 1989. She was the first paid co-ordinator of the AWHC, taking on the job after funding had been obtained when the demands of the AWHC's work became more than could be done by Sue Neal, our volunteer secretary. Judi worked tirelessly for the Council, organising fundraising book fairs, writing grant applications, attending hundreds of meetings including those of the newly formed Auckland Area Health Board. She also played a major role in the formation of the Federation of Women's Health Councils in 1990 and subsequently worked in a volunteer role as the first convenor of the Federation for several years.

Judi was also involved in the hui on maternity services consumer representation held at the Manukau Institute of Technology in Otara on Saturday 25 November 1989. The meeting was attended by around 50 women and Task Force members,

Ray Naden, Anne Nightingale, Sam Denny and Yvonne Underhill-Sem. The result of this meeting was the formation of the Auckland Maternity Services Consumer Council in 1990.

Debbie Payne, the first convenor of the Maternity Services Consumer Council, said that the MSCC was Judi's brain child in that it was her idea to set it up as an umbrella group similar to the Federation of Women's Health Councils. Judi helped Debbie set up the first meeting of the MSCC Steering Group in 1991 and for the first year MSCC meetings took place in Debbie's home as Debbie was on a year's maternity leave at the time.

At the beginning of 1995 Judi resigned from both the AWHC and the Federation of WHCs.

She then went on to set up the Women's Health Information Unit at National Women's Hospital where she became renowned for her commitment to ensuring women (and health professionals) had access to the latest evidence-based information on a wide range of women's health issues.

In 2004 Judi was appointed Director of Advocacy at the office of the Health and Disability Commission, a position she held until November 2014. She was a tireless champion of health and disability consumer advocacy and of the Code of Rights in her role as Director. Judi also served as a consumer member of the national Quality Improvement Committee, where she championed consumer voice.

Judi was a very private person, and always refused any attention or acknowledgement of her many

achievements. She would definitely not have approved of this article. However, as others have observed "a great kauri has fallen" and those left behind want to celebrate the life and untimely death of this unique, determined and very humble woman.

Lynda Williams

AUTUMN COURSES AT THE AUCKLAND WOMEN'S CENTRE

The Auckland Women's Centre has a number of activities and courses on offer over the autumn.

They include exercise classes – both a Restorative Yoga class and a Sacred Tantra Bellydancing course – and a Women's Book Club that meets on the 3rd Sunday of the month from 4–6pm.

There are also a number of free activities, including Sunday Single Mums' SKIP Meet Ups on Sundays 1.30-3.30pm, Feminist Action on the first Wednesday of every month from 7 – 9pm, and Lesbian DVD/Games nights on the last Wednesday of every month from 7-9pm.

A Building a New Life after Separation workshop has been scheduled for Saturday 21 March, and a Girls' Self Defence workshop for girls aged 7–12 years on Friday 27 4-6pm and Saturday 28 March 10am-4pm.

Affordable, confidential counselling is also available at \$40 - \$80 a session.

Bookings are essential.

For further information contact the Auckland Women's Centre on phone (09) 376-3227, email at info@awc@womens.org.nz or visit their website www.awc.org.nz

PATIENTS HARMED IN CLINICAL TRIALS NOT COVERED BY ACC

Few patients who agree to take part in clinical trials understand the difficulties that they face should they be harmed as a result of a drug they are given or a device they agree to be used or have implanted during a clinical trial.

It is not widely known that the Accident Compensation Corporation does not provide cover for research participants who consent to being enrolled in research trials that are sponsored by international drug companies and who are subsequently harmed as a result of the treatment they receive during the trial. While patients receive a Participant Information Sheet (PIS) with a standard statement about their not being covered by ACC if the clinical trial is sponsored by an overseas drug company but are covered if the trial is sponsored by a New Zealand institution or company, it is extremely doubtful that they have any idea of what this means.

Many New Zealanders are aware that making a claim to ACC can sometimes be problematic and prolonged. Such difficulties pale in comparison to the nightmare world they will enter should they be harmed during a clinical trial and then find themselves having to single-handedly take on the might of an international drug company and its insurance company's lawyers.

The Ministry of Health and the ethics committee members are very aware of the problem which the AWHC has been told came about as a result of

drastic cuts made to ACC's budget in the early 1990s.

The minutes of the meeting of the Northern A ethics committee held on 9 December 2014 record:

"The Committee discussed sponsored trials, injuries and the relationships between sponsors, insurance companies and participants. The Committee discussed how a sponsor should assure the Committee that participants will be adequately supported during any disputes made by the insurance company in relation to a participant claim, and that it is the sponsor's obligation to satisfy the participant (the participant is indifferent to any business between the sponsor and the insurer.)" (1)

During the December 2014 meeting Brian Fergus, the chairman of the Northern A ethics committee, stressed to several of the researchers that they must make it clear to the sponsor of their research trial that it is the sponsor's responsibility to deal with all claims for the harm suffered by a research participant, rather than withdrawing from negotiations and leaving the patient to deal with the insurance company lawyers.

However, researchers are also in an invidious position, caught between a rock and a hard place. It should not be left to researchers to sort out the sponsor of their research trial.

The Minister of Health and the government must immediately rectify this unfair and unethical system.

References

1. <http://ethics.health.govt.nz/about-committees/meeting-dates-venues-minutes/northern-minutes/northern-minutes-2014>

TIME TO COME CLEAN ON BREAST SCREENING

The February 2015 issue of the National Screening Unit's newsletter *Screening Matters* features an article announcing that "BreastScreen Aotearoa (BSA) is reviewing its health education resources to ensure they are meeting the needs of women and effectively communicate the latest information on the harms and benefits of population breast screening." (1)

This review is long overdue as New Zealand women are still not being given evidence-based information on the lack of effectiveness of breast cancer screening programmes. However it is extremely unlikely that a health agency whose role is to promote screening can be entrusted with the task of providing good information on the risks of breast cancer screening and lack of evidence that it saves lives.

In February 2015 Lynda Williams travelled to Sydney for the weekend to hear presentations by Don Benjamin, Convenor and Research Director of the Cancer Information & Support Society in Sydney, and Professor Peter Gotzsche, Director of the Nordic Cochrane Centre in Denmark, on cancer screening.

Don Benjamin

In his presentation Don Benjamin outlined the principles of running and interpreting results from randomised controlled trials, summarised the results of breast, bowel, prostate, lung, and ovarian cancer screening trials, and summarised the levels of overdiagnosis resulting from cancer screening.

He began with a brief history of cancer treatment and then described

the old cancer paradigm – cancer is a systemic disease, so identify and treat causes, and then examined the new paradigm – cancer starts locally and later spreads so “get it all, and get it early.”

Before it can be assumed that cancer interventions, particularly surgery or screening, are effective it is necessary to provide reliable evidence of benefit. Of course, the gold standard of evidence is the randomised controlled trial (RCT) which Don Benjamin went on to talk about in some detail.

And this is where it gets tricky and somewhat confusing, especially when it comes to measuring efficacy. In answer to the question what do the results of a well-run randomised controlled trial evaluating treatment look like, Don said:

- After a trial is completed the number of deaths **from all causes** in the treated group is compared with the number of deaths **from all causes** in the control (untreated) group.
- All causes include cancer mortality and non-cancer mortality.
- Non-cancer mortality should not be affected by screening or treatment.

After showing that RCTs revealed that “getting it all” has no proven effect on survival or mortality, Don then went to show that early surgery was equally ineffective.

“In 1996 I analysed the results of the seven RCTs evaluating breast cancer screening and concluded that screening does more harm than good:

- Screening does not reduce overall (all cause) mortality
- Radiotherapy was used differently in the screened and control groups (in breach of the RCT rules)

- This meant that many women who would have died from breast cancer instead died from heart failure making it appear that there had been a reduction in breast cancer deaths (confounding factors).

This lack of proof of overall benefit was subsequently confirmed in 2001 by Peter Gotzsche and by William Black et al in 2002.”

Don then described how RCTs have also revealed the lack of efficacy of early surgery – as a result of screening – for lung cancer, prostate cancer, ovarian cancer and bowel cancer. He ended his presentation by discussing the harms of screening in terms of both overdiagnosis and the resulting overtreatment.

In summary:

“There are no significant benefits from screening for breast, bowel, lung, prostate or ovarian cancers.

There is significant harm resulting from overdiagnosis of breast and prostate cancers.

There is harmful overtreatment for breast, lung, prostate and ovarian cancer.

So there is not only no survival benefits from ‘getting it all’ or ‘getting it early,’ but attempts to do so result in significant overdiagnosis and harmful overtreatment.”

Peter Gotzsche

Peter Gotzsche’s lecture was based on his 2012 ground-breaking book “Mammography Screening” Truth, Lies and Controversy” which takes an evidence-based, critical look at the scientific disputes and the information provided to women by governments and cancer charities. It also explains

why mammography screening is unlikely to be effective today. (2)

A copy of the Nordic Cochrane Centre’s booklet on Mammography Screening is available in a variety of languages including English at:

<http://www.cochrane.dk/>

The discussion that followed the presentations from both men revealed that many of the women in the audience were unaware of the risks of mammography screening and were shocked and dismayed at what they had just heard.

Alexandra Barratt

On 3 March 2015 *the British Medical Journal* published Alexandra Barratt’s paper “Overdiagnosis in mammo-graphy screening: a 45 year journey from shadowy idea to acknowledged reality.” (3) Alexandra Barratt is a professor of public health at the University of Sydney and was one of the speakers at the Preventing Overdiagnosis conference held at Oxford University in September 2015.

In the “How to do better” section of her paper Professor Barratt referred to the need for quality information for patients:

“Many women continue to be prescribed or encouraged to undergo screening rather than being supported to make an informed choice. Women should be given information that has been carefully developed and tested, because information is an intervention that may have both positive and detrimental effects.

Screening targets for screening services should be questioned, and consideration should be given to ensuring the provision of balanced information – for example, using the

“consider an offer” approach outlined by Entwistle and colleagues in 2008. Practitioners should not be incentivised to achieve participation, nor should high participation in screening be regarded as a marker of health service quality.” (3)

In conclusion the AWHC hopes that BreastScreen Aotearoa will rise to the challenge in Professor Barratt’s paper and revise their nine pamphlets, two booklets, three posters and five information sheets to present women with the balanced information they need to make an informed choice about screening.

References

1. <https://www.nsu.govt.nz/news/screening-matters-issue-50-february-2015/bsa-health-education-resources-being-reviewed>
2. Peter Gotzsche. “Mammography Screening: Truth, Lies and Controversy.” Radcliffe Publishing 2012.
3. <http://www.bmj.com/content/350/bmj.h867?etoc=>

AWHC GENERAL MEETING 26 February 2015

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

- Financial reports and audit
- Grant applications
- NEAC discussion document
- Peter Gotzsche’s lectures
- Northern A ethics committee
- 2015 Cartwright conference

Further information on some of the topics listed above is contained in this issue of the AWHC newsletter.



AUCKLAND WOMEN'S HEALTH COUNCIL AGM

The Auckland Women’s Health Council’s AGM will be held on Thursday 26 March 2015.

Time: 4 – 5pm

Date: Thursday 26 March 2015

Venue: AUT Akoranga Campus,
Akoranga Drive, Northcote, Auckland

For further information contact the Council on (09) 520-5175 or email: awhc@womenshealthcouncil.org.nz

AWHC NEWSLETTER SUBSCRIPTION

The newsletter of the Auckland Women’s Health Council is published monthly.

COST: \$30 waged/affiliated group
\$20 unwaged/part waged
\$45 supporting subscription

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

Send your cheque to the Auckland Women’s health Council, PO Box 99-614, Newmarket, Auckland 1149.

UP AND COMING EVENTS

DISTRICT HEALTH BOARD meetings for March/April 2015:

Waitemata DHB (Website address: www.waitematadhb.govt.nz)

The Waitemata Hospital Advisory Committee meeting starts at 11am on Wednesday 8 April 2015 and will be followed by the DHB Full Board meeting which starts at 1.30pm. Both meetings will be held in the DHB Boardroom, Level 1, 15 Shea Terrace, Takapuna.

The **combined Waitemata DHB and Auckland DHB** Community & Public Health Advisory Committee meeting starts at 2pm on Wednesday 18 March 2015.

Auckland DHB (Website address: www.adhb.govt.nz)

The Hospital Advisory Committee meeting will be held at 9.30am on Wednesday 1 April 2015 followed by the Full Board meeting at 2pm. Both meetings will be held in the A+ Trust Room in the Clinical Education Centre, Level 5, Auckland City Hospital.

Counties Manukau DHB (Website address: www.cmdhb.org.nz)

The Community & Public Health Advisory Committee meeting will be held at 1.30pm on 15 April 2015 at 19 Lambie Drive, Manukau City.

The Hospital Advisory Committee meeting will be held at 9am on Wednesday 25 March 2015 at Ko Awatea and will be followed by the Full Board meeting at 1.30pm.



ETHICS COMMITTEE meetings – dates for the four MOH ethics committees are at:

<http://www.ethics.health.govt.nz/about-committees/meeting-dates-venues-minutes>



The Auckland Women's Health Council and Women's Health Action

will be co-hosting a Cartwright conference to mark the 27th anniversary of the release of the Cartwright Report –

“The Future of Screening: balancing the benefits and risks of cancer screening.”

Date: Friday 7 August 2015.

Venue: Fickling Centre, Three Kings, Auckland

Further information will be available in due course.