



# AUCKLAND WOMEN'S HEALTH COUNCIL NEWSLETTER

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## Father speaks out about HPV vaccine

Last month the UK newspaper, *The Independent*, featured the following article by father of two Jerome Burne.

"Much as I love my two gorgeous daughters – aged 13 and 17 – and wish to protect them from all harm, I will not be consenting to them having the HPV vaccine against cervical cancer.

It's a public health initiative that is unnecessary, reckless and ridiculously expensive. Worse, serious doubts about its wisdom have not been properly presented to the public. Instead, children and parents have been bombarded with publicity – "a totally life-saving, revolutionary vaccine" – while the media have largely parroted official assertions that it is "safe, proven and effective", all of which are unfounded.



The outline of the project is pretty familiar. This term, "the biggest public health programme ever" began to vaccinate all 12 and 13-year-olds against the human papilloma virus (HPV): this involves three separate injections over several months. Later

on, 16- to 18-year-olds will be inoculated as part of a catch-up programme. By July 2011, more than two million girls will have been offered the vaccine which, it is claimed, will protect them against the two strains of HPV – numbers 16 and 18 – responsible for 70% of all cervical cancers.

At the moment, 3,000 women develop cervical cancer every year and just under 1,000 die from it. Government and drug-company press releases claim that the programme will eventually cut these deaths by about 400 a year. What's not to like?

To begin with, it is a fabulously expensive way to deal with a problem which, although horrible for anyone who develops it, is hardly a major health risk. Figures haven't been widely publicised, but one quoted cost is £100m a year, which works out at £250,000 per life saved. Would this pass the NICE criteria for expensive cancer drugs? We already have a very effective screening programme that has brought deaths from cervical cancer down from 11 per 100,000 in 1950 to 3.4 in 2004, and the numbers are expected to continue falling.

However, the vaccination could actually reverse that. Women still have to be screened because, even when the whole programme is up and running, the number who develop precancerous cells is expected to drop by, at best, 50%. At the moment, the biggest risk factor for cervical cancer is never having been screened; half of those with the disease haven't. The fear is that the programme may reduce screening

attendance as vaccinated women assume they are safe.

But these are arguments about the HPV vaccine as a public policy. What really matters to me and every parent is: what risk does it expose my children to? As we've seen that the chance that any individual girl will benefit is tiny, I want the risk of any adverse reaction to be even tinier. Public discussion of risks in the UK gives little hint of possible dangers. (The figures that follow all relate to a brand called Gardasil being used in America. This was to have been the UK choice until one called Cervarix was chosen because it was cheaper. We are told that otherwise they are equivalent.)

We plan to vaccinate 600,000 12- and 13-year-olds a year, on the basis of trials involving fewer than 1,200 girls under 16 that lasted less than two years. More than 20,000 women aged 16 to 26 were also involved in trials. Side effects included birth defects and juvenile arthritis. Only a few; but what happens when millions get the vaccine? Could certain genotypes be particularly vulnerable? No one knows. In fact, I'm asked to enter my children into a vast experiment.

Already, patterns of side effects are emerging. A body called Justice Watch has been prising figures for adverse reactions to Gardasil from the US authorities. Last October, the total was around 3,500; by this July, the figure had risen to 8,864, including 18 deaths and 140 "serious" reports.

There's plenty of disagreement over what the cases show. Authorities say they aren't necessarily connected to the vaccine. Two of the most worrying reactions have been blood clots – what might that be doing if you are one of the older girls on the pill? – and 38 reports of an autoimmune disorder called Guillain-Barré syndrome that can cause paralysis.

It's obvious that we need more information, which is why the US Food and Drug Administration called for studies to investigate these possible risks. But the results won't be in for a decade in some cases. The quickest trial they asked for was one involving 44,000 vaccinated girls who are being followed for six months to pick up signs of any immediate or medium-term problems such as autoimmune disorders or rheumatism. The results will be out in September next year. Meanwhile, UK experts confidently declare that there are no dangers; if so, why run this and the other studies?

But the uncertainty over side effects isn't all that's unknown. A key factor in the success of any vaccine is the length of time it confers protection. If it is too short – say, less than 10 years – too many booster shots will be needed. How long will protection last? No one knows; so far, it's lasted six years.

Then there is the reaction of the 15 other HPV strains, which account for 30 per cent of the cancers; will that change as the two most infectious ones are blocked? Could it allow them to become more infectious? A recent paper in the New England Journal of

Medicine explored the possibility. Will it happen? No one knows.

And on top of all that, we don't actually know that the vaccine will prevent cancer. We know it confers resistance to the virus strains most likely to cause cancer, but since the cancers don't usually appear until a woman is in her late forties, definitive proof will be some time coming. So this great public-health initiative looks more like a hugely unstable edifice of wildly optimistic assumptions piled on top of one another. If just one or two prove way out, it could all come crashing down. It's one lottery I won't buy a ticket for.

HPV infects the majority of women, maybe as many as 80 per cent, by the age of 50 but it very, very rarely causes a problem. I believe that my girls will be a lot safer relying on healthy immune systems that haven't been challenged by too many vaccinations and on regular, cheap, simple and safe smear tests."

- Jerome Burne. *The Independent* 18 November 2008.



## REVIEW OF HDC ACT and CODE OF RIGHTS

The Health & Disability Commissioner has recently released a consultation document on the review of the Health and Disability Commissioner Act and the code of Consumers' Rights.

It is 14 years since the Health and Disability Commissioner Act was enacted and over 12 years since the Code of Consumers' Rights became law on 1 July 1996. The HDC Act requires the Commissioner to undertake regular reviews of both the Act and the Code to consider whether any changes are necessary or desirable. This is the HDC's third review – the two previous reviews were undertaken in 1999 and in 2004.

The first review was undertaken by Robyn Stent, the first Commissioner. That review and the 2001 Cull Report on the Review of Processes Concerning Adverse Medical Events resulted in a number of changes to the Act that were set out in the HDC Amendment Act which came into force in September 2004. The key amendments were improvements to the complaints resolution processes and they enabled the Commissioner to deal more effectively with complaints, helped reduce the duplication of process, and assisted with early resolution of complaints.

Another less desirable outcome of the first review was the amendment that was subsequently made to Right 7(10) of the Code. This significant change to the Code was approved by Cabinet in 2003. Prior to this amendment, Right 7(10) provided that

“any body parts of bodily substances removed or obtained in the course of a health care procedure may be stored, preserved, or utilised only with the informed consent of the consumer.” In Robin Stent’s view “it is entirely appropriate for a provider, who wishes to use a body part or bodily substance for a purpose different from that for which consent was initially obtained, to go back and obtain informed consent for any new use,” and she did not agree with the submissions made by interested groups (ie researchers and health professional groups rather than consumers/consumer groups) that the requirement for consent needed to be changed. (1)

Unfortunately Ron Paterson, the second Commissioner did not agree and without any further consultation with consumers, he “supported the amendment because of evidence that the Right 7(10) requirement for informed consent had, in some cases, hindered valuable public research, and audit and evaluation activities.”

The second review took place in 2004 prior to the legislative reforms of the *Health Practitioners Competence Assurance* coming into force. As Commissioner Ron Paterson states in the current consultation document: “As the main concerns I had with the operation of the Act and the Code were about to be addressed by these changes, I concluded that further substantial amendment was not necessary or desirable at that stage.”

However, the AWHC and a few other consumer groups disagreed. In its

submission on the 2004 review the Council registered its opposition to the changes made to Right 7(10) and its concern at the dangerous precedent that had been set by changing the Code of Consumers’ Rights without consultation with consumers.

The Council also tellingly commented: “If Guthrie cards are to be used for anything else than the purpose for which they are currently being used then there must be wide spread consultation, the development of educational material that explains both the changes and the options that consumers have to demand the return or destruction of the Guthrie card, and the establishment of a special ethics committee that is charged with overseeing the Guthrie card database.”

Given the current situation re the push by researchers who want unauthorised access to the two million Guthrie cards currently held in storage and the intense debate raging over such “secondary” uses of Guthrie cards (see following article), the changes made in 2004 to Right 7(10) which have allowed this to occur have become a major concern.

Written submissions are due by 28 February 2009, and can be emailed to [hdc@hdc.org.nz](mailto:hdc@hdc.org.nz) or posted to Review of HDC Act and Code, Health & Disability Commissioner, PO Box 12299, Wellington 6144.

**References:**

1. “A Review of the Health & Disability Commissioner Act 1994 and Code of Rights for Consumers of Health and Disability Services.” February 1999.

## **GUTHRIE CARDS IN DANGER OF BECOMING A NATIONAL DNA DATABASE**

The blood taken from babies through a heel-prick test and placed on a card known as the Guthrie Card has been stored indefinitely and is now in danger of becoming a de facto national DNA database. More than two million DNA samples are currently stored with the National Screening Unit and there are cards dating back nearly 40 years to when the heel-prick test was first introduced in New Zealand in 1969.

The newborn baby blood sample is collected for the purpose of screening newborns for 28 metabolic disorders. About 45 affected babies are detected each year.

Privacy Commissioner Marie Shroff has raised concerns over what the data could potentially be used for in a submission to the Health Ministry and has recently spoken out on national radio about the plans to continue storing the cards. Ms Shroff believes the cards should be destroyed after 16 years as parents have not given permission for their child's Guthrie card to be stored indefinitely, or for the card to be accessed and used by a third party.

The National Screening Unit has come under pressure from public health researchers to retain the cards and make them available for research. However, Ms Shroff believes that before that happens there needs to be wide public consultation. If the cards are not destroyed she wants a completely

separate body to be set up and legislation enacted to protect this database from secondary uses.

She is also concerned that their storage beyond the screening period could allow the blood to be used for genetic screening for employment or for criminal purposes.

The Ministry of Health expects to make recommendations on the newborn screening programme to the new Health Minister Tony Ryall next year.

### **Returning the Guthrie Card**

Those parents who wish to have their child's Guthrie card returned to them can write to the National Testing Centre, PO Box 872, Auckland for a form to fill in, or download the 2-page form from the National Screening Unit website. Parents can only apply to have the card returned if the child is under 16 years of age. For those 16 years and over the request must be made by the young person or adult.

As the form is really difficult to find on the NSU website, try googling "return of Guthrie card" instead.



## INCREASE IN ASTHMA LINKED TO CAESAREANS

A study of nearly 3,000 children in the Netherlands who were followed from birth through to the age of eight revealed those born by caesarean section had nearly twice the risk of developing asthma by 8 years of age.

Dr Henriette Smit of the National Institute for Public Health and the Environment also reported that the chance of developing asthma was even greater when, in addition to the caesarean section, children had two allergic parents. For caesarean-born children with one allergic parent the risk of asthma was about the same as in the entire sample.

This is the second large study published this year to link caesarean section with the subsequent development of asthma. A study of 1.7 million Norwegian children, published in June in the *Journal of Pediatrics*, found a 50% increase in asthma risk associated with those who had a caesarean delivery.

Exposure to bacteria during birth is thought to play a key role in priming the immune system, providing a defence against the development of allergies. In caesarean children, exposure to bacteria happens later and research has shown they have different intestinal flora – gut bacteria – suggesting the maturation of their immune system is delayed.

- Caroline Roduit et al. "Asthma at 8 years of age in children born by caesarean section." *Thorax An International Journal of Respiratory Medicine*. December 2008.

## AWHC GENERAL MEETING 27 November 2008

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

- Financial reports
- COGS grants total \$12,000
- Changes to AWHC's constitution
- Submission on MOH Maternity Action Plan
- New gov't's funding of Herceptin
- Gardasil campaign
- Review of HDC Act and Code
- WHA 5 August 2009 conference



### AWHC NEWSLETTER SUBSCRIPTION

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

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Send your cheque to the AWHC, PO Box 99-614, Newmarket, Auckland.

# UP AND COMING EVENTS

**DISTRICT HEALTH BOARD** meetings for January/February 2009:

**Waitemata DHB (Website address: [www.waitematadhb.govt.nz](http://www.waitematadhb.govt.nz))**

The Community & Public Health Advisory Committee meeting starts at 1pm on Wednesday 10 December 2008 and will be followed by the Hospital Advisory Committee meeting at 2.30pm.

Waitemata DHB Full Board meeting starts at 1pm on Wednesday 28 January 2009 and meets in the DHB Boardroom, Level 1, 15 Shea Terrace, Takapuna.

**Auckland DHB (Website address: [www.adhb.govt.nz](http://www.adhb.govt.nz))**

All Auckland DHB meetings are held all on the same day (now on the first Wednesday of the month) in the Marion Davis Library, Auckland City Hospital. The Community & Public Health Advisory Committee meeting is at 9am on Wednesday 4 February 2009. This will be followed by the Hospital Advisory Committee meeting at 11am and then the Full Board meeting at 1.30pm.

**Counties Manukau DHB (Website address: [www.cmdhb.org.nz](http://www.cmdhb.org.nz))**

The CMDHB Full Board meeting will be held at 1pm on Wednesday 4 February 2009 at 19 Lambie Drive, Manukau City.

The Hospital Advisory Committee meeting will be held at 9am on Tuesday 27 January 2009 and will be followed by the Community & Public Health Advisory Committee meeting at 1pm.



**TABS (Trauma and Birth Stress)** is holding a Study Day on Friday 13 February 2009. Entitled *Identifying and caring for People with PTSD after Childbirth* the Study Day will be held at the CCS Training Room at 14 Erson Avenue, Royal Oak, Auckland. **Cost:** \$99 Early Bird registration; but it will be \$125 for registrations received after 12 December. Includes lunch.

- For further information email: [akfeb09@tabs.org.nz](mailto:akfeb09@tabs.org.nz) or phone (09) 575-7404.