AUCKLAND WOMEN'S HEALTH COUNCIL

NEWSLETTER

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HDC ANNUAL REPORT

In December 2012 Health & Disability Commissioner Anthony Hill released his annual report covering the period from 1 July 2011 to 30 June 2012.

New format
The latest annual report is in a completely new format to previous reports. The reports from the Director of Advocacy, the Deputy Commissioner, Disability and the Director of Proceedings have been dispensed with, along with photos of any of the HDC staff – with the exception of the Commissioner. The Commissioner's "foreword" is followed by a section on the role of the Commissioner. Section 3 which focuses on the HDC's key activities includes nine case studies.

Complaints resolution
During the 2011/12 the HDC received 1,564 complaints (compared to 1,405 the previous year) and responded to around 5,000 enquiries.

Advocacy
The advocacy service which consists of 48 advocates (41 FTEs) is located in 25 community-based offices around the country. Over half the core advocates are Maori. Six advocates are specialist advocates with three working with the deaf community and three working with refugee/migrant communities.

The report states that "the advocacy service managed 10,816 enquiries for the year, with 98% of the enquiries closed within two days and 99% within five days."

1,380 complaints closed
Of the 1,380 complaints resolved during the 2011/12 year, 140 complaints were referred to advocacy, (compared to 208 for the previous year), 142 were referred to other agencies such as the Privacy Commissioner, ACC, the Ministry of Health, DHBs, or Human Rights Commission, (compared to 154 for the previous year), and 79 were withdrawn or resolved by the parties or by the Commissioner (compared to 66 for the previous year.

Some complaints were resolved by referral to providers (203 compared to 255 for the previous year) and two were resolved by mediation.

Section 38(1)
Closing or resolving complaints by the use of Section 38(1) occurs when, in the Commissioner's "discretion," no further action is considered "necessary or appropriate," eg, because there is no apparent breach of the Code, or because matters are already being addressed through other appropriate processes or agencies. Over half of all complaints (690 of 1,380) complaints were closed this way in the 2011/12 year compared to 557 the previous year.

Investigations and Inquiries
Of the 1,380 complaints only 44 were closed after a formal investigation was undertaken. The 44 investigations resulted in 29 reports which found there had been a breach of the Code of Consumers' Rights. There were eight referrals to the Director of Proceedings.

The low numbers of investigations and breach findings are extremely concerning and raise questions about the functioning and resourcing of the HDC office, as well as how complaints about health providers are being dealt with. The current approach under-

mines the accountability regime envisaged by the HDC Act, since consumers lose the benefits of formal investigation findings, and are denied access to the Human Rights Review Tribunal (HRRT) if there are so few breach findings. Even if the Commissioner essentially upholds the complaint but takes "no further action," the consumer cannot take a case to the Tribunal without a formal investigation and breach finding.

It is also noteworthy that, half way through his five-year term as Commissioner, Anthony Hill has not undertaken any "own initiative" inquiries, such as Robyn Stent's Canterbury Health inquiry and Ron Paterson's North Shore hospital inquiry. The ability to initiate a major inquiry is a significant power that can be used to investigate serious systems issues in the health and disability sector, eg medical devices such as metal on metal hip replacements, the gynaecological mesh, and breast implants that have caused great harm to patients.

Proceedings

Another consequence of so few investigations and breach findings, is a drop in referrals to the Director of Proceedings of providers found in breach of the Code. There were only eight referrals of providers to the Director. There was one substantive hearing before the HRRT, three cases were dealt without the need for a formal hearing and one case concerning an obstetrician was concluded by negotiated agreement without the HRRT being asked to make orders.

According to the Medical Council Annual Report 2012, there was only one charge brought by the Director of Proceedings prosecutions before the Health Practitioners Disciplinary Tribunal (HPDT) – compared with six charges resulting from prosecutions by Professional Conduct Committees set up by a registration authority. The original Cartwright model of prosecutions independent of the health professions has been turned on its head.

Backlog

Even though the HDC is undertaking fewer investigations and prosecutions, the backlog of open files is growing. At 30 June 2010, shortly before Anthony Hill took office, there were 323 open files; by 30 June 2012, that had ballooned to 557 open files, an increase of 72% over two years. The age of open files is also increasing. In 2010 there were no files open over two years; the 2012 Annual Report does not specify the number, but notes that 30 files were over 2 years old at the time of closure. It seems that the lengthy delays in the complaint system, reported by Helen Cull QC in her 2001 inquiry, have returned – bad news for complainants and providers.

Combined with reports of a very high turnover amongst the Complaints Resolution staff at the HDC, and the early departure of experienced Deputy Commissioners Rae Lamb and Tania Thomas since Anthony Hill became Commissioner, the state of the HDC is of serious concern to consumers. What has happened to our public watchdog?

- The HDC report is on the HDC's website: www.hdc.org.nz

"GIVE US THE MIRACLE DRUG"

At the end of January the front page of the *NZ Herald* featured a by now familiar story of a small group of patients that were desperately lobbying for a very expensive drug. (1) In this case it was the world's most expensive drug – costing $500,000 a year per patient. (2)

The drug in this story is eculizumab, otherwise known as Soliris, and it is used to treat patients with PNH (paroxysmal nocturnal haemoglobinuria) which is an extremely rare blood and immune system disorder. The *Herald* article stated that in New Zealand "up to 20 people are thought to have PNH" with eight of them considered candidates for Soliris.

PNH

PNH is an acquired rather than genetic disease characterised by the destruction of red blood cells, blood clots, impaired bone marrow function, and a 3-5% risk of developing leukaemia. The red blood cells become prone to destruction by parts of the person's own immune system due to the lack of a special protein which normally protects the red blood cells from being destroyed by the immune system. It is closely related to aplastic anaemia, and up to 30% of newly diagnosed cases of PNH evolve from aplastic anaemia. The median survival after diagnosis is 10 years; however some patients can survive for decades with only minor symptoms. (3)

The drug company

Soliris is manufactured by Alexion Pharmaceuticals which has given its new drug to three of the eight New Zealand patients with PNH under a compassionate access scheme. It is not clear why the drug company has chosen to fund only three of the eight.

Towards the end of the *NZ Herald* article it was revealed that there was a New Zealand support group for patients with PNH and they had begun this lobbying campaign which was being funded by Alexion. A follow-up editorial in the *Herald on Sunday* reported that the support group had been given an "unrestricted educational grant" from Alexion and the campaign was being orchestrated by Viva, a Sydney PR firm that represents Alexion Pharmaceuticals. (4)

The editorial referred to the fact that "Alexion is a NASDAQ-listed firm that last year projected a net revenue of $1.35 billion from sales of Soliris around the world." (4) $1.35 billion from just one drug! It's enough to make the Ministry of Health's eyes water.

The editorial continued: Alexion is "not just a world leader in the medical laboratory; it's a world leader in arm-twisting governments to fund its extortionately-priced drug." The pressure is being applied by slick campaigns that appear to be run by patient groups, but are in fact being run by Alexion's PR firms in Australia and Canada.

The New Zealand patient group which was established less than a year ago has a very professional website that features a video of Dr Humphrey Pullon, a consultant haematologist in Hamilton, alerting us to "the developing public scandal that is seriously ill PNH patients being denied access to a life-saving treatment." (5) His promotion of Soliris is even accompanied by a soundtrack.

There is also an online "PNH petition for life" for us all to sign or download.

According to the *Herald on Sunday*, "these campaigns are effective: 24,000 Australians signed a petition supporting the nation's 70 PNH sufferers, forcing the federal government to begin funding the drug in 2011. The Canadian government also capitulated – though that nation's provinces banded together to knock down Alexion's prices. They were aided in their hardball negotiations by the discovery that Alexion was supplying Soliris to the US at half the price it was quoting to the rest of the world." (4)

A visit to the Wikipedia website on Soliris in the course of researching this article revealed that the site had recently been updated to include the fact that New Zealand is the only country in the OECD that does not fund Soliris. Its reference is the TV3 news item on 24 January that repeated what was in the *NZ Herald* article that morning. This "important" fact also features on the NZ PNH support group's website.

A link on another PNH support group's website to an article on long-term treatment with Soliris published in 2011 in *Blood,* the weekly publication of the American Society of Hematology, showed that all the researchers had financial ties to Alexion Pharmaceuticals. (6)

Another toxic drug

The drug.com website states that "Soliris affects your immune system, and using this medication may increase your risk of serious infection such as meningitis. You must be vaccinated against meningococcal infection at least 2 weeks before you start treatment with Soliris. If you have been vaccinated in the past, you may need a booster dose." (7)

Alexion Pharmaceuticals' own website states that the US product label for Soliris includes a boxed warning advising that "life-threatening and fatal meningococcal infections have occurred in patients treated with Soliris. Meningococcal infection may become rapidly life-threatening or fatal if not recognised and treated early." (8)

Of course this fact isn't included on the New Zealand patient group website. What is there is the claim that "Our only hope for survival rests in the hand of PHARMAC."

Actually, it doesn't. It rests in the hands of Alexion Pharmaceuticals which can certainly afford to lower the price of its obscenely over-priced drug. The PNH Support Association of NZ should be lobbying Alexion Pharmaceuticals, not NZ taxpayers.

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ABORTION SUPERVISORY COMMITTEE REPORT

The Abortion Supervisory Committee's 35th annual report to Parliament for the year ending 30 June 2012 arrived in the mail just before Christmas. It was a significant year for the ASC on a number of fronts.

Abortion numbers decline
The report reveals that the numbers of induced abortion in New Zealand are continuing to decline with the numbers for the 2011 year being the lowest for 12 years.

Seven years of litigation ends
Having had to devote considerable resources to the *Right to Life vs Abortion Supervisory Committee* case over the past seven years, the Abortion Supervisory Committee welcomed the final judgment of the Supreme Court dismissing Right to Life's appeal. The judgment issued on 9 August 2012 upheld that of the Court of Appeal, which found that the ASC is not empowered to examine the individual decisions of certifying consultants in relation to the authorisation of individual abortions.

ASC appears at Select Committee
In May 2012 the ASC appeared before the Justice and Electoral Parliamentary Select Committee for the first time in ten years. Topics discussed included the standardised referral system introduced two years ago, the declining number of certifying consultants, overall aging of the work-force, and the ASC's work to improve local access to services.

Statistics
The total of induced abortions performed in 2011 was 15,863 compared to 16,630 in 2010, 17,550 in 2009, 17,940 in 2008 and 18,382 in 2007, a significant and continuing decrease given the increase in the population over those five years.

The report states that the Committee is pleased that the sharpest decline has been in the child and teenage groups. The number of abortions for 11 – 14 year olds has declined from a high of 105 in 2006 to 68 in 2011.The number of abortions for 15 – 19 year olds has declined from a high of 4,173 in 2007 to 2,822 in 2011.

The number of medical abortions as opposed to surgical abortions has remained much the same with a rate of 6.3% (1,000) in 2011.

Women aged between 20-24 years accounted for 5,160 of the abortions performed, women aged 25-29 years accounted for 3,340 abortions, and women aged 30-34 accounted for 2,220 abortions. There were 55 abortions for women over 45 years.

Contraception Used
A total of 8,270 women (52.1%) were not using any form of contraception, 4,470 (28.2%) were using condoms, 1,808 (11.4%) were using combined oral contraceptives, and 443 (2.8%) were using progesterone only contraceptives. A total of 209 women (1.3%) had used emergency contraception, 271 were using natural family planning (1.7%), 230 (1.4%) were using an intra-uterine device, and 108 (0.7%) were using depo provera injections.

The ASC notes that there has been no improvement in the proportion of women having an abortion who were not using any contraception at the time of conception and note that this

continuing unfavourable trend is an area that requires further research.

Repeat terminations
The Committee is concerned that there is no decline in the number of terminations of pregnancy sought by women who have already had two or more abortions. The report states that the "key to reaching these women will be further increasing the availability of various forms of long-term contraception as well as increasing access to publicly funded tubal ligation or ablation so that unwanted pregnancies are avoided. It is concerning to note that the number of publicly funded tubal ligations performed has been declining."

Ethnicity
The ethnicity graphs revealed that there were 9,044 abortions for European women, 3,855 abortions for Maori women, 2,649 for Asian women, 2,054 abortions for Pacific women, and 189 for Middle Eastern, Latin American and African women.

Access issues
The report noted that there is a shortage of certifying consultants in some large provincial towns, such as Whanganui and Invercargill, as well as in a number of smaller towns throughout New Zealand.

The Committee heard distressing reports from certifying consultants where they, their families, patients and the wider public have been the subject of harassment. Women seeking fertility services were also harassed when they were mistakenly thought to be seeking termination of pregnancy services.

Medical staff in Invercargill are being harassed as a result of the abortion services now being provided at Southland Hospital.

Consultant fees
The report reveals that the fees paid to the 170 certifying consultants totalled $4,427,120 (ext GST) in the year ended 30 June 2012.

Decriminalising abortion
The report notes that the ASC has established contact recently with the Ministry of Health through its Elective Services Group, and comments hopefully that "although the Contraception, Sterilisation and Abortion Act 1977 is administered by, and the Committee is supported by, the Ministry of Justice, contraception, sterilisation and abortion are health, not justice, issues and this new liaison with the Ministry of Health will prove valuable."

A copy of the full report is available on the Ministry of Justice website: http://www.justice.govt.nz/tribunals/abortion-supervisory-committee/about-the-abortion-supervisory-committee

ABORTION THEN & NOW
New Zealand abortion stories from 1940 to 1980

Margaret Sparrow's groundbreaking book, published by Victoria University Press in 2010, uses the stories from women to describe four decades of abortion history in New Zealand. It contains a wealth of information and insight, and demonstrates that after more than 30 years it is long past time for legislative change.

UP AND COMING EVENTS

DISTRICT HEALTH BOARD meetings for February 2013:

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

The **combined Waitemata DHB and Auckland DHB** Community & Public Health Advisory Committee meeting starts at 2pm on Wednesday 13 February 2013.

Waitemata Hospital Advisory Committee meeting starts at 11am on Wednesday 27 February 2013 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.

Auckland DHB (Website address: www.adhb.govt.nz)
The Hospital Advisory Committee meeting will be held at 9.30am on Wednesday 20 February 2013 followed by the Full Board meeting at 2pm. Both meetings will be held in The Marion Davis Library at Auckland City Hospital.

Counties Manukau DHB (Website address: www.cmdhb.org.nz)
The Hospital Advisory Committee meeting will be held at 9am on Tuesday 26 February 2013 and will be followed by the Community & Public Health Advisory Committee meeting at 12.30pm at 19 Lambie Drive, Manukau.

The Counties Manukau DHB Full Board meeting will be held at 1pm on Wednesday 6 March 2013 at 19 Lambie Drive, Manukau City.

ETHICS COMMITTEE meetings – dates for the four new ethics committees are at:
http://www.ethics.health.govt.nz/about-committees/meeting-dates-venues-minutes

'Gender Matters: Determining Women's Health'

The Australian Women's Health Network is holding its 7th Australian Women's Health Conference in Sydney from 7 – 10 May 2013.

The conference will focus on showcasing cutting edge research and best practice approaches in women's health policy and practice locally, across Australia and internationally.

For further information go to http://www.womenshealth2013.org.au/