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Commonwealth contribution to former forced adoption policies and practices

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DES Action Australia-NSW

Submission

Senate Community Affairs Committee

Inquiry: Commonwealth contribution to former forced adoption policies and practices.

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Summary

DES (diethylstilboestrol) was an anti-miscarriage drug prescribed to pregnant women from 1938-1971 (and sometimes beyond). This drug caused serious potentially life threatening problems. Women given DES and their children of that pregnancy are at higher risk of certain types of cancer and reproductive problems. DES exposed people need special vital preventive health care. DES was administered as a lactation suppressant, sometimes as overdose, to Forced Adoption Victims without informed consent. Circumstances warrant expert investigation of cancer incidence and health status of Forced Adoption Victims administered DES as lactation suppressant. There should be an official national public apology to Forced Adoption Victims for the administration of the drug, DES (sometimes as overdose) without informed consent.

Background

Diethylstilboestrol (DES or commonly known as "stilboestrol") is a synthetic oestrogen that was developed to supplement a woman's natural oestrogen production. It was first prescribed in 1938 for women experiencing miscarriages or premature deliveries and originally considered effective and safe. DES was available in the form of tablets, injections, vaginal suppositories (also called pessaries) and sometimes as an ingredient in pregnancy vitamins. In 1971 physicians were advised to stop prescribing DES to pregnant women because it was linked to a rare vaginal/cervical cancer in female offspring. Since 1971 research has shown:

- Women prescribed DES while pregnant, known as DES mothers, are at 30% increased risk for breast cancer and require annual mammography and clinical breast examinations.
- Women exposed to DES before birth (in the womb), known as DES daughters, are at increased risk for clear cell adenocarcinoma (CCA) of the vagina and cervix, have almost two times increased risk of breast cancer after age 40, reproductive tract

structural differences, pregnancy complications and infertility. The risk for developing CCA is about 1:1000 DES daughters. Although DES daughters appear to be at highest risk for clear cell cancer in their teens and early 20s, cases have been reported in the 30-50 age groups [http://obgyn.bsd.uchicago.edu/registry.html#accessions] . This cancer is aggressive; it can be symptomless and is not always detected by the usual Pap smear. It should be detected early. DES daughters require life-long special annual "DES examinations", along with annual mammography and clinical breast examinations. DES daughters also require high-risk care during pregnancy.

- Men exposed to DES before birth (in the womb), known as DES sons, are at risk for non-cancerous epididymal cysts (cysts behind the testicles).

Researchers are still following the health of the DES exposed population to determine whether other health problems occur with age and whether subsequent generations are affected. There is recent research showing menstruation irregularity in DES granddaughters, which hints the possibility of increased risk of infertility. There may be many people who do not know whether they were exposed to DES and some women may not remember taking DES. DES information is important because people who were exposed must be vigilant about their own health care – to detect cancers early, demand high risk obstetric care when pregnant and factor in their exposure when making decisions about HRT use. It is as much part of a person's medical history as a family history toward heart disease or diabetes.

The Adverse Drug Reactions Unit of the Therapeutic Goods Administration (TGA) has data of 18 case reports of DES associated cancer. The failure to report cases has been acknowledged, thus rendering the TGA's database unreliable. There has also been refusal by the TGA to complete regular reciprocal cross-checks of Australian cases that have been reported to the International DES Registry, held in Chicago, USA.

Prior to the DES problem, the cancer type linked to DES was rare and typically occurred in post-menopausal women. Data held by the Institute of Health and Welfare (AIHW) 1982-2006 shows 42 cases <age50, and 142 cases of the DES-type cancer across all ages in the general population. In State Cancer Registries prior to 1982 there are 20 further cases of DES-type cancer in the general population. With the known risk of 1:1000 DES daughters developing the associated cancer, this means there are conservatively at least 42,000 DES daughters, the equivalent number of DES sons and 84,000 DES mothers, thus providing a minimum estimate of 168,000 DES exposed Australians. There is no upper age limit for the development of DES-type cancer, with cases now occurring in DES daughters in the 40s and 50s age group. Therefore, the data from State Cancer Registries and the AIHW across all ages show there could be up to 648,000 DES daughters, DES mothers and DES sons in Australia.

In 2004 the TGA issued a media release about DES gaining nation-wide media attention. However, this media release contained information mistakenly stating that the increased cancer risks for DES daughters had now passed and that DES daughters no longer require their special annual "DES examinations" for their life-saving cancer prevention. In lobbying government, the organisation DES Action Australia-NSW eventually required legal assistance to ensure that a media release with correct information was issued by the TGA. In 2008 the

TGA issued a further media release with information that DES daughters require life-long follow-up with annual DES examinations. Unfortunately, this 2008 media release did not receive nation-wide media attention.

Due to the time lapse, doctors are unable to track down Australians exposed to DES. It cannot be presumed that doctors have already alerted affected patients about their DES exposure. There has been no public health education campaign by any Australian government to help alert the many DES exposed Australians who are still oblivious to the fact of their exposure, unaware of the harmful effects of DES, and unaware of the special health care they require, including their special vital cancer preventive health care. The public's response to DES Action Australia-NSW following intermittent media attention to DES exposure over the years shows that the health of DES exposed victims has been neglected due to the absence of prominent public information about DES - information which would have prompted earlier access to their rightful health care. Since the 1990s the Australian government has continued to advise DES Action Australia-NSW that raising public awareness of DES could create unnecessary anxieties for women who may not know if they have been exposed to DES.

In 2001 the USA Centers for Disease Control launched the first national public education campaign to educate the US public and physicians about DES (www.cdc.gov/des). The US campaign launch included an extensive media campaign across USA. Australian government information about DES is buried in websites, significantly decreasing the chance that the population would become aware in the first instance that there is any health problem associated with DES. It is the opinion of DES Action Australia-NSW that it is the right of Australians to be informed of the possibility of having been exposed to this dangerous drug. Accordingly, lobbying efforts over the past 5 years have been directed to the Australian government towards ensuring the promotion of information about DES exposure directly to the public in health programs. The situation remains that many people are suffering the effects of DES exposure, without knowing why and what they can do about it.

DES Usage as Lactation Suppressant

DES was approved for usage as a lactation suppressant (to help dry up breast milk) in 1941. In 1968 research showed this DES usage to have risk of thrombosis (blood clot) and pulmonary embolism (blood clot in the lung). This usage was not withdrawn until 1978. It was mainly given in the form of tablets, but was also available as injections and may have been given in liquid oral form. We have received anecdotal reports of its availability for usage in injection form in maternity units and hospitals in the 1980s. There is literature stating that DES principally relieves breast engorgement when lactation commences and will only reduce the milk supply in some cases. It is stated, too, that warm compresses applied to the breasts are also effective. To date, there has been no further research to study the possibility of other adverse effects of DES given as a lactation suppressant.

Reports of Lactation Suppressant Usage by Callers to DES Action Australia-NSW

We have received a report that during the 1940s at a Sydney hospital, DES was administered routinely as lactation suppressant in liquid oral form to women not intending to breastfeed (including unmarried mothers). These women consented to this medication upon being told that the liquid would help dry their milk. The reporter recalled that the women were

unaware of the name of the drug being given. The reporter also doubted that the nurses were even aware that DES had been dispensed in the medicine glasses. The liquid oral form was discontinued after a few years. Reports made to our organisation show that from the 1950s, tablet form was common. We have one report of an initial dose in injection form, followed by a course of tablets.

Reporters who were married mothers have stated that an explanation of DES tablets was given prior to their consent for its administration. Of the very few reporters to our organisation who were unmarried mothers, the majority have been unable to remember whether explanation of the DES drug was given or whether they gave consent for its administration. Their inability to recall could be partly explained by anecdotal evidence in government records suggesting that unmarried mothers were given large doses of sedative drugs, particularly at labour and in the days after birth. However, one unmarried mother reports having been administered DES without informed consent. Most of the unmarried women learnt that they had been administered DES by later acquiring their health records. Only one unmarried mother stated she was satisfied the consent procedure.

A married mother reported that whilst medicated with DES, she provided expressed breast milk for premature babies. A further married mother reported having an abundance of breast milk whilst taking DES and was instructed to breast feed the babies for adoption in the hospital nursery. Several married mothers have reported continuing to feed their babies whilst medicated with DES tablets. To our knowledge there has been no research to show absence of adverse effects of newborn infants ingesting DES. In 1980, incidences of pseudo precocious puberty (breast enlargement and vaginal bleeding) were found in young children in Italy due to ingesting DES treated veal contained in homogenised baby food.

The Role of the Commonwealth in the Practice of DES Usage in Forced Adoption Victims

Our organisation is aware of reports in government documents showing that DES was administered post-delivery to Forced Adoption Victims for the purpose of suppressing lactation, without informed consent. It is also documented in government records that exceedingly large amounts of DES were administered to these women. We have anecdotal information of instances where dosages were three times that recommended.

Possible Reason/s for the Administration of Overdoses of DES

In government documents it is stated that the sizeable doses of DES were administered to Forced Adoption Victims to achieve effect. However, we have no information that married mothers were afforded the same overdoses to achieve effect. There is evidence that DES interacts with Phenobarbital (sedative) to cause decreased activity of DES in dogs and cats. There is no information available in public data that would indicate the same drug interaction in humans. However, information about this interaction may exist in the complete data held by manufacturers of DES. Should this interaction occur in humans, then this would provide a possible reason for administering overdoses to Forced Adoption Victims who were sedated with Phenobarbital during and after delivery. In any case, for whatever reason that overdoses were administered, it calls into question as to how the dosage for a “safe” overdose could ever possibly have been calculated for the Forced Adoption Victims.

We have anecdotal information of a survey in government records showing approximately 80% incidence of breast/cervical/ovarian cancers among a group of 120 Forced Adoption Victims, members of Origins NSW. As this incidence seemed extraordinarily high, we made enquiry to Origins NSW to recheck this information. Our enquiry confirmed this shocking survey result. The Commonwealth has a role in the above matters and a duty of care in addressing these issues.

The Potential Role of the Commonwealth

The above circumstances warrant an official nation-wide investigation by experts of the health status (including cancer incidence) of Forced Adoption Victims who were administered DES as a lactation suppressant. In particular, the reported over-zealous usage of the dangerous drug, DES, by way of **overdoses**, should be investigated for the possibility of causing adverse effects. This investigation should include a systematic comparison of DES dosages given to married women for the suppression of lactation, and any possible adverse effects on these women.

Forced Adoption Victims who were given DES in this manner should be informed of investigation results and of any necessary associated health care measures. Accordingly, married women given DES as lactation suppressant should be informed of any adverse effects of DES and any associated health care required. As remediation, there should be an official national public apology to Forced Adoption Victims for the administration of DES, sometimes as an overdose, without informed consent.