

Submission

Senate Legal and Constitutional Affairs References Committee

Inquiry into Donor Conception

Carol Devine
Coordinator, DES Action Australia-NSW
14 Edmundson Cl
Thornleigh NSW 2120

Background

Diethylstilboestrol (DES) 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. 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, 80% increased risk of breast cancer after age 40, reproductive tract structural differences, pregnancy complications and infertility. The risk for developing CCA is 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. **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. With the known risk of 1:1000 DES daughters developing the associated

cancer, this means there are conservatively at least 18,000 DES daughters, the equivalent number of DES sons and 36,000 DES mothers, thus totalling at least 72,000 Australians affected. There has 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. There are 40 cases of the DES cancer type in the <50 age group held in Australian Institute of Health and Welfare (AIHW) data. However, these cases have not been investigated regarding DES exposure. Prior to the DES problem, the cancer type linked to DES was rare and typically occurred in post-menopausal women. In view of this, the AIHW data provides a more accurate estimate, showing at least 168,000 DES daughters, DES mothers and DES sons in Australia. The AIHW data across all age groups indicates this figure could be as high as 568,000.

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 they 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. However, this media release did not receive nation-wide media attention.

Doctors are unable to track down Australians exposed to DES. There has been no public health education campaign by 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. Since the 1990s the Australian government has continued to issue advice 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. Many people are suffering the effects of DES exposure, without knowing why and what they can do about it.

Relevance of the issue of DES exposure to this Inquiry

Donor conception issues are relevant to DES exposed Australians due to the fact that infertility can be a consequence of DES exposure. Since 1995 DES Action Australia-NSW has shared the interests and concerns of the Donor Conception Support Group.

Response to Reference Points

- a) donor conception regulation and legislation across federal and state jurisdictions;

Legislation should be consistent across States to ensure equity for Australians. Clinics should be regulated to adhere to Australian medical and ethical standards and be operated in a manner that is transparent to both government and the public.

- b) the conduct of clinics and medical services, including:
 - i) payments to donors

As it is a donor program involving the point of human conception, we believe donor payments are inappropriate and unethically make human conception by itself a commercial commodity. We do not consider that donors should be paid beyond basic reimbursement for travel expenses.

- ii) management of data relating to donor conception

Data management of clinics should be consistent across Australia in respect to the data content provided to clients and in the mode of information delivery to donors, recipient parents and offspring. The retention of records should be consistent across Australia and the period of retention appropriate for the needs of donors, recipient parents and offspring.

- iii) provision of appropriate counselling and support services

Existent counselling services should be expanded for the provision of counselling for past clients of donor conception. Comprehensive counselling services should be reinstated to allow counsellors the time and resources to undertake investigative processes that are necessary to provide clients the information they need from donors.

- c) the number of offspring born from each donor with reference to the risk of consanguine relationships

Limitation on the number of offspring born from each donor should be continued, even though the chances of consanguinity are thought to be slight. Respect for the emotional stress due to the off chance of consanguinity between donor conception offspring should be upheld. In considering the issue of consanguinity, it should be noted that a great many donor offspring have not been told how they were conceived.

- d) the rights of donor conceived individuals

Donor conceived individuals should be afforded rights to establish their family background identities and to be informed of their conception donors wherever possible, just as similar

rights have been afforded Australian adopted children. Accordingly, their rights for proper health care would follow, since a more accurate family medical history could be determined for individuals. Similar to child adoption legislation, donor conception legislation should be fully retrospective.