

## Submission

### Environment and Public Affairs Committee

#### Inquiry into past forced adoptive policies and practices

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## Introduction

In March 2023 Scotland's former First Minister Nicola Sturgeon included the use of the drug, DES (diethylstilboestrol or "stilboestrol") in her historic apology to forced adoption women. Here is the relevant quote from the First Minister's apology speech:

*And we will continue to explore with those affected, the key challenges that they face with regard to adoption records – and the lasting health impacts faced by mothers who were given Stilbestrol. On that final point, I want to emphasise again today the importance of women attending their routine breast and cervical screening appointments.*

The apology by Sturgeon, which included reference to DES, was inspired by one forced adoption woman, Marion McMillan, who is now a cancer patient.

( <https://www.sundaypost.com/fp/three-words-to-change-the-world/> )

Following the apology speech during Question Time, Miles Briggs MSP expressed concern that an investigation into the long-term health impact of DES usage as lactation suppressant on forced adoption women should take place. ( <https://youtube/xNHIUWKxvuE> ) There are several Scottish Members of Parliament supportive on this issue.

Since the apology in Scotland, there have been calls in the UK for a public inquiry into DES, as well as a public awareness campaign about DES. The Scottish Parliamentary speech by Caitlin McCarthy (US DES Daughter activist, Screenwriter of *Wonder Drug*) has been instrumental towards this, as well as to the apology and its associated media reports.

( <https://drive.google.com/file/d/1mDQPmqvE19lQ8ZqL1hdjXT-vPVhtXIYZ/view?fbclid=IwAR15SD3phiyeB-OW5Pkg0lfyIglUI5jVPRz-Yj9qlx7Kcd0ybgHifRHMzls> )

Further activism by McCarthy has resulted in former US Senators John Kerry and Scott Brown jointly obtaining an acknowledgement of DES as a “tragedy” from the FDA in 2011. Her activism continues, where currently US Congressman Jim McGovern is seeking an apology for the DES tragedy and the restoration of research funding from the US Department of Health and Human Services.

(<https://www.worcestermag.com/story/lifestyle/health-fitness/2023/02/28/u-s-rep-james-mcgvorn-calls-for-formal-government-apology-on-des/69895336007/> )

DES was an anti-miscarriage drug prescribed to pregnant women in many countries, including Australia, 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, reproductive problems, and numerous health conditions. DES exposed people need special preventive health care. Comprehensive information about DES can be sourced at the website of DES Action USA ([www.desaction.org](http://www.desaction.org)). DES was also administered to women post-birth as a lactation suppressant to help dry up breast milk. The organisation DES Action NSW has received reports Australia-wide revealing that DES was administered as a lactation suppressant to forced adoption women, sometimes as overdose, and in the main, without informed consent.

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## **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. DES was a so-called “wonder drug” and now it is known as the “silent Thalidomide”. Many Australians are unaware of the fact of their exposure and the adverse health effects of DES. Some women may not remember taking DES. Research (sourced from [www.desaction.org](http://www.desaction.org) ) has shown:

- Women prescribed DES while pregnant, known as DES mothers, are at a modestly increased risk for breast cancer.
- Women exposed to DES before birth (in the womb), known as DES daughters, are at an increased risk for clear cell adenocarcinoma (CCA) of the vagina and cervix, increased risk for breast cancer after age 40, reproductive tract structural differences, pregnancy complications and infertility. The risk for developing CCA is 1:1,000 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 up to age 55. There is no upper age limit for this cancer occurring in DES daughters. This cancer is aggressive and should be detected early. DES daughters are also at risk for endometriosis, uterine fibroids, paraovarian cysts, adenosis, early menopause, rheumatoid arthritis, depression (possibly), cardiovascular disease, diabetes, and osteoporosis.

- Men exposed to DES before birth (in the womb), known as DES sons, are at increased risk for cryptorchidism (small and/or undescended testes), non-cancerous epididymal cysts (benign genital growths), hypospadias (urethral opening in the wrong place), testicular inflammation/infection, microphallus (smaller than average penis), testicular varicoceles (varicose vein on the testicle, infertility, testicular cancer (possibly), prostate cancer (possibly), cardiovascular disease, diabetes, and osteoporosis.
- Research about DES grandchildren has shown delayed menstruation regularity (which may increase risk of infertility ), skipping periods, having preterm birth delivery, uterine defects (possible), higher genital defect risk in grandsons (possible), hypospadias, birth defects in grandchildren (possible), and ADHD risk (possible).

In Australia from the late 1950s to the mid-1970s, DES was a medical treatment to reduce the height of tall girls. In the 1990s the lobby group Tall Girls Inc. petitioned the government for a follow-up study due to their health concerns and that their families were unaware that this DES treatment was experimental. The need for a follow-up study was also raised independently by endocrinologists. These actions resulted in research led by Dr Alison Venn, Epidemiologist, University of Tasmania. The women of Tall Girls Inc., given their investment in the project, were involved from inception in the study design process.

( <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3247030/> ) Results were published in 2004, showing that women who had been given DES to reduce their adult height had higher risk of fertility problems. Whilst explaining the Tall Girls study in a recent media interview, Distinguished Professor Emerita Alison Venn states that studies of this type are generally difficult, but may not be impossible. [Poison in the Womb BBC <https://www.bbc.co.uk/sounds/play/m001jsq1> (20:03 mins)]

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. 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), with its non-mandatory reporting, has data of some case reports of DES associated cancer (CCA).

The failure to report cases has been acknowledged. Consequently the TGA's database is not reliable for estimating the magnitude of the DES problem in Australia. 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.

Prior to the DES problem, the cancer type linked to DES (CCA) was extremely rare and typically occurred in post-menopausal women. Data held by the Institute of Health and Welfare (AIHW) 1982-2019 shows 231 cases of the DES associated cancer across all ages in the Australian population. In State Cancer Registries prior to 1982 there are 20 further cases of DES associated cancer. With the known risk of 1:1000 DES daughters developing the associated cancer, this means there are an estimated 251,000 DES daughters, the equivalent number of DES sons and 502,000 DES mothers. Therefore, the data from State Cancer Registries and the AIHW across all ages up to 2019 show there could be an estimated total 1,004,000 DES daughters, DES mothers, and DES sons in Australia. There may have been further case reports since 2019 that would raise this total estimate figure.

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 NSW eventually required legal assistance to ensure that a further 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 cancer preventive health care. The public's response to DES Action NSW following intermittent media attention to DES exposure over the past shows that the health of DES exposed Australians has been neglected, largely 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 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 2003 the USA Centers for Disease Control launched the first national public education campaign to educate the US public and physicians about DES. This multi-million dollar project was the result of lobbying by the organisation DES Action USA ([www.desaction.org](http://www.desaction.org)). 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 are any health problems associated with DES. It is the opinion of DES Action NSW that it is the right of Australians to be informed of the possibility of having been exposed to this dangerous drug. Lobbying efforts, all to no avail, 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 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. 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 to DES Action 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 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. One unmarried mother reported having been administered DES without informed consent. However, 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 that would 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 Practice of DES Usage in Forced Adoption Women**

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 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.

In government documents it is stated that the sizeable doses of DES were administered to forced adoption women 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 same interaction occur in humans, then this would provide the possible reasoning behind administering overdoses to forced adoption women 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 have been calculated for the forced adoption women.

### **Report of Potential Health Impact of DES Usage as Lactation Suppressant**

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 women, 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. No attention has been given by government to this survey.

## **COMMENTS IN CONCLUSION**

In accordance with the Scottish Parliamentary Apology in March 2023, there should be a government public acknowledgement of the usage of DES to suppress lactation in forced adoption women in Australia, which should also include a stated intention to investigate its long-term health impacts. As was done in Scottish Parliament, forced adoption women should also be urged to attend their routine breast and cervical screening appointments.

In view of the aforementioned circumstances under past Australian policies and practices outlined by DES Action NSW, there should be serious view towards a research follow-up study. The 2004 Tall Girls Study by Distinguished Professor Emerita Alison Venn would set a precedent for such research. Indeed, there are distinct parallels between the scenario of DES usage in forced adoption women in Australia and that of the Tall Girls, in particular with the raised concerns of potential health impacts by those who were administered DES and with the issue of consent for its administration.