

# DESPATCH

no.1 sept. 1980

NEWSLETTER of DES ACTION p.o. box 282, camberwell, victoria

**D.E.S.** (diethylstilbestrol) is a medically prescribed drug.

The problems outlined here are the direct result of the prescription of a drug assumed to be safe and effective at the time. Because of this, some doctors are reluctant to face all the implications of DES-exposure: their role in prescribing DES and their responsibility to those affected.

It is our experience that some doctors are resistant to seeing that DES-exposure is a serious health problem - they either dismiss DES as "nothing to worry about" or regard it as an over-reaction by those affected.

Some doctors appear to have a compulsive desire to reassure at all costs. Some are unaware of the correct screening tests; and they provide inadequate and/or incorrect information to their patients.

**DES ACTION;** is a community group formed in Melbourne late in 1979.

We believe that the DES story should be told; and those affected supported. It is important that the dangers and tragic legacy of this medically prescribed drug be officially recognized and widely acknowledged by the government and the medical profession  
SO THIS SITUATION WILL NEVER HAPPEN AGAIN.

## THE DES MESS

Diethylstilbestrol (DES) is a powerful synthetic estrogen which was prescribed to many pregnant women in the mistaken belief it prevented miscarriage. The use of the drug during pregnancy has now been linked with genital-tract abnormalities, sterility and cancer in both DES daughters and sons.

### HOW DID IT HAPPEN?

DES was synthesized by Sir Charles Dodd in England in 1938. Forty years ago drug companies could market and promote a drug without having to first prove its safety; or even that it worked! Within months of being synthesized, DES was being marketed throughout the world. No toxicity tests on animals were ever done; and there were never any controlled trials with human subjects.

### THE SMITHS OF BOSTON.

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The first promoters of DES as a therapy for high-risk pregnancies were a husband-and-wife team: Dr. George V.S. Smith, head of the

Gynecology Department of Harvard University Medical School from 1942 to 1967; and Dr. Olive Watkins Smith, a biochemist.

The Smiths were well-respected in the field and had done impeccable research during the 1930s. They were among the first to demonstrate how hormones function and fluctuate over the course of the menstrual cycle. From the mid-1930s on, the Smiths published many, many papers on estrogen excetion in normal pregnancy. They observed low hormones levels in some women spontaneously aborting.

In 1941, the Smiths theorized that perhaps the newly developed DES might maintain these high-risk pregnancies; and they simply prescribed DES for this purpose. There were no controlled studies: the Smiths just started prescribing stilbestrol to a number of pregnant women attending the Boston Lying-In hospital (the prestigious maternity hospital associated with Harvard University).

The Smiths wrote in glowing and subjective terms about the apparent success of DES in maintaining high-risk pregnancies. Despite the decidedly 'unscientific' nature of their work (eg. no control group; no objective measurements just subjective observations) the many articles were published in the most prestigious and influential medical journals eg. New England Journal of Medicine, American Journal of Obstetrics & Gynecology.

These articles have an almost evangelical feel. For example, in a typical article in 1946 (OW Smith, GVS Smith & Hurwitz: Am. J. Obst. & Gynec., 51: 411, 1946) the Smiths give a very detailed outline of the DES treatment they recommended to prevent miscarriage. They then state "We would appreciate reports from others (obstetricians) stimulated by this publication to try it. In this way sufficient data should be collected in a relatively short time to be of statistical significance."

It must be emphasized that these exact dosage instructions could have been read and followed by any doctor anywhere in the world (including Australia) who felt 'stimulated' by the Smiths' glowing reports to prescribe DES: the new, readily-available and inexpensive "wonder drug."

#### WOMEN AS GUINEA-PIGS:

In 1948, Dr. Olive Watkins Smith reported on their first major study. (OW Smith: Am. J. Obst. & Gynec. 56: 821, 1948). This involved 632 DES-treated pregnancies dating back to 1943. In all, 117 obstetricians throughout the USA had co-operated by following the Smiths' DES regimen and by pooling their results. By this stage the Smiths were convinced that DES was effective for many pregnancy complications, including miscarriage and diabetes.

The following year the Smiths completed their second major study. (OW Smith & GVS Smith: Am. J. Obst. & Gynec. 58: 994, 1949). This study was carried out at Boston Lying-In hospital between April 1947 and Jan. 1949; and was reported at the annual conference of the American Gynecological Society in May 1949.

It compared the pregnancies of 387 women who were prescribed DES throughout pregnancy, with 550 who were not. The study was not well designed as the untreated group was simply that: untreated. The DES-treated mothers received extra care and attention.

What is 'interesting' about this study is that all the pregnant women were having normal first pregnancies

In order to get the treated and untreated groups as homogenous as possible, the Smiths limited their experiment to healthy first-time mothers. Women with known illnesses such as diabetes or high blood pressure (ie. all high-risk pregnancies!) were excluded.

These women were never informed that that were taking part in an experiment. Some now recall they were told the pills were vitamins.

The Smiths reported enthusiastically that the babies of the DES-treated women were "unusually rugged": DES not only produced "bigger and healthier" babies, it also rendered a normal pregnancy "more normal".

#### D.E.S. ALWAYS CONTROVERSIAL:

Right from the start the use of DES was controversial. At the 1949 conference, where the Smiths presented their research, a number of queries were raised.

Dr. E. Page, San Francisco:

"(I)t is difficult to believe that such a potent drug as stilbestrol will prove to be (like an essential vitamin) necessary for the most successful outcome of normal pregnancies."

Dr. W.M. Allen, St. Louis: was rather puzzled as:

..!(In the pregnant rabbit) the administration of estrogen is very deleterious to the fetus.

In early pregnancy estrogen will prevent implantation or produce abortion; and during later stages it will lead to death of the fetus"

Dr. W.J. Dieckmann, Chicago: pointed out that the untreated group in the study was not given a placebo, a procedure he considered essential to scientific accuracy. He announced that he would undertake such a scientific study at Chicago University

#### THE DIECKMANN-CHICAGO UNIVERSITY STUDY

This is a genuine 'scientific' experiment with a treatment group (given DES) and a control group (given a placebo). It has become the basis of many recent studies into the effects of DES on daughters, sons and mothers. (Many 'DES researchers' eg. Bibbo, Gill, and now Herbst, are at Chicago University and have access to these records and participants.)

The original study was undertaken at Chicago Lying-In Hospital and involved the 2,000 women who registered there between Sept. 1950 and Nov. 1952 (WJ Dieckmann, ME Davis, LM Rynkiewicz & RE Pottinger: Am. J. Obst. & Gynec. 66: 1062, 1953) It was concluded that DES has no therapeutic value in pregnancy.

So 12 years after the Smiths started treating pregnant women with DES, the Chicago University study showed that DES was completely useless for this purpose.

DES was ill-researched and its use was always controversial. Probably the most bitter pill we have to swallow is the fact DES did not work. There is now evidence that DES actually increases miscarriages, fetal deaths and stillbirths.

## " THE BOSTON CANCER."

In 1966 at Massachusetts General Hospital a 15 y.o. girl was diagnosed as having clear-cell cancer (adenocarcinoma) of the vagina. This was most unusual as this cancer was (until DES) one of the rarest types of cancer; and it was usually seen in much older women. Within the next few years 7 similar cases of clear-cell adenocarcinoma of the vagina and cervix in young women turned up at MGH. All victims were young, the eldest being 22. All but one were DES daughters (the 8th victim's mother had been prescribed a combination of estrogen and progesterone).

( Today, some 14 years later, the USA DES cancer register numbers well over 400 young women with this DES-induced cancer. The number of young Australian victims is completely unknown. There has been no attempt to set up an Australia DES register; and no attempt to even warn DES daughters of their potential risk. )

## THE HERBST REPORT.

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A report of the link between DES-exposure in utero and the development of clear-cell cancer of the vagina and cervix in DES daughters by Arthur Herbst and colleagues was published on April 22, 1971. (AL Herbst, J Ulfelder & DC Poskanzer :N.Eng.J.Med. 282:878, 1971)

In the USA, the Food and Drug Administration (FDA) banned the use of DES in pregnancy on 10th Nov. 1971

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Much of this information is culled from: Women and the Crisis in Sex Hormones by Barbara Seaman & Gideon Seaman. (Bantam Books: NY, 1978) This book gives an excellent, easy-to-read account of the DES story.

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# SO WHAT ARE WE LEFT WITH?

Since 1971, medical journal articles have documented more and more effects of DES-use during pregnancy. The situation has been compared to a series of 'time bombs' exploding one after another, 20 to 30 years after the drug was prescribed.



## DES DAUGHTERS.

All DES daughters are potentially at risk of developing the clear-cell adenocarcinoma of the vagina and cervix. This is a rare (estimated risk is 1.2 cases per 1,000 DES daughters), aggressive and symptomless cancer which requires special screening procedures - a Pap smear will not necessarily pick up this cancer. This cancer usually develops before the age of 30, resulting in hysterectomy. DES daughters must know about their DES-exposure, and the need to have these special tests every 6 months.

It is suspected that DES daughters may have an increased risk of other types of genital-tract cancers. This means they must have careful screening for years to come.

Many daughters have an increased risk of developing certain pre-cancerous conditions of the cervix and vagina. These must be watched very carefully so they don't develop into anything more sinister.

Medical authorities in the USA recommend that DES daughters avoid any added estrogen (eg. the oral contraceptive pill). This is another reason DES daughters should be aware of their exposure: so they can weigh up the risks of taking 'the pill'.

It now appears that many DES daughters may have a very characteristic malformation of the upper genital-tract (ie. uterus, tubes and ovaries). As a result of this, a DES daughter may have difficulty in becoming pregnant, or carrying that pregnancy to term. This is a third reason she must know she is a DES daughter: so she can take extra care and have additional check-ups during pregnancy.

DES SONS may also develop genital-tract problems - including cysts, undescended testes, underdeveloped genitalia, lowered sperm count and sterility - as a result of their exposure to DES in the womb.

They may also have an increased risk of developing cancer of the testes. DES sons must also know about their exposure so they can take appropriate action to safeguard their health, including regular self-examination of the testes and an annual medical check-up.

DES MOTHERS are also victims. They appear to have an increased risk of breast and genital cancer. As with DES daughters, it is recommended that DES mothers avoid additional estrogen intake (eg, estrogen replacement therapy for menopausal symptoms).

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For a more detailed account of the effects of DES on daughters, sons and mothers, plus an outline of the correct screening procedures, write for: 'DES Fact Sheet'

P.O. Box 282  
Camberwell 3124

( Please enclose \$2.00 for copying and postage costs. )

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Our experiences within the group show that you may not get the correct information from your doctor, nor the correct referral. Not all doctors are aware of DES; and what screening procedures are necessary.

If you would like to know more about the procedures to take, and some of the pitfalls to avoid, we are most willing to help you.

Contact: DES ACTION  
P.O. Box 282  
Camberwell 3124

## DES ACTION: VICTORIA

For most of us in DES ACTION the term DES has been part of our vocabulary for less than a year. However one of our members, Bon Hull, has been aware of the DES issue for several years.

1974 After reading an article in a (US) magazine, Bon wrote to the USA, requesting information on DES. Since then she has been receiving information on DES and material on others areas of women's health from the Boston Women's Health Collective.

1976 There was an article on DES published in the Age. The issue then 'died': there was no follow-up nor official action taken either by the medical profession or the government. Some DES-exposed women were lucky enough to see this small amount of publicity, and sought appropriate medical attention.

However, as there was no official attempt to alert or follow-up those women prescribed DES in Victoria (and elsewhere in Australia), most of us remained unaware, and at risk.

1977 Bon started writing her book on women's health 'In Our Own Hands' (which has just been published). By this stage she had collected alot of information on DES; and had contacted DES ACTION/San Francisco. This group has continued to send us information, and has been very supportive of our attempts to get a group going.

1979 In July/August, Wendy Lowenstein read Bon's manuscript. When she came to the section on DES, Wendy suddenly twigged that she was probably directly involved ie. as a DES mother.

Wendy, an enthusiastic 'doer', then rang the Union of Australian Women (UAW) with which she has been associated for many years, and asked if any women's groups were involved with this important health issue. The answer was "No".

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The UAW agreed to take up the DES issue, and asked Yvonne Smith to organize things. The choice was an excellent one as Yvonne is a quietly efficient and effective organizer. She did an enormous amount of 'hack' work at the end of last year - organizing meetings and writing many letters to women's groups, health groups and to politicians.

The DES Action Group (Interim Committee) was formed and the first meeting was held in the UAW rooms on the 24th September, 1979. This was followed by a second meeting on the 8th October, chaired by Yvonne with Wendy presenting material on DES summarized from Bon's book. Then on the 24th October, the UAW held a luncheon where Bon spoke on the DES issue.

At the same time as this sequence of events, and independent of it, DES received some publicity in the media:

Early in September 'Nationwide' on ABC TV featured a segment on DES. The parents of a DES daughter who had died of the clear cell cancer were interviewed. Also at this time the Age featured a series of articles on DES.

It was through this minimal amount of publicity that several members of DES ACTION (myself included) first heard of DES, and realized that they were directly involved. Thus having been alerted, we were able to link with the October meetings organized by Yvonne and Wendy.

The DES Fact Sheet grew out of my need to get the facts straight in my head. Also I was sick of being told by doctors not to believe what I read in the newspapers: I thought a fully documented report in 'their' dry language would have to be taken seriously. With Bon's help I compiled and ordered all her material, plus I up-dated it in at the medical library.

The first draft of the Fact Sheet was ready when DES ACTION members - Margaret Goodman, Bon Hull, Yvonne Smith and myself - nervously ascended to Mr. Borthwick's very palatial office suite for our deputation on the 13th February. ( See the Borthwick Saga. )

DES ACTION slowly consolidated and became viable this year. We have held regular meetings this year and have slowly grown in both numbers and determination.

The main thing I want to emphasize is that DES ACTION comprises very

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The main thing I want to emphasize is that DES ACTION comprises very ordinary people - DES mothers and daughters, and other concerned individuals. We are not radicals or 'professional' activists: just average, sensible people who are becoming increasingly incensed at the apathy and inaction of the government and the medical profession on this serious health issue.

- Marian Vickers.

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DES ACTION/Victoria thanks:

Bon Hull - for the information and time shared.

Wendy Lowenstein - for enthusiasm, contacts and post box.

Jean Melzer - for providing our venue and copying facilities.

UAW - for being concerned about the DES issue when other groups were not; and for providing initial support and facilities.

DES ACTION/San Francisco and Pat Cody - for providing articles, suggestions and support.

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# ralph nader...

## meets des action

On the 24th July 1980, DES ACTION members Felicity Browning, Bon Hull, Beryl Pausacker and Marian Vickers went to Ralph Nader's public meeting at Dallas Brooks Hall. We felt the topic "People, Power & Information" was of particular relevance to the present situation of DES ACTION.

The format of the evening was 3 speakers with a half-hour question time at the end. Questions had to be written on the yellow slips of paper provided.

Felicity had drafted the following question, which we directed to Ralph Nader:

" What is the current status of the synthetic estrogen diethylstilbestrol (DES) in the USA; and how can Australian DES ACTION groups bring about government recognition of and protection against the effects of this dangerous drug."

We were sitting down the front of the hall, feeling rather 'powerless' as we could see the hundreds of yellow question slips being shuffled and vetoed. However, to our great surprise and delight, ours was the first question asked!!

Ralph Nader corrected the chairman in his pronunciation of di-ethylstil-be-strol; gave a very brief outline of the effects of DES on daughters; and said he couldn't believe DES was still being used here as it was under "emergency suspension" in the USA. He then suggested we write to his Health Research Group in Washington for further information.

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# BORTHWICK

## \* The ~~Foray~~ Saga

2nd Nov. 1979 Yvonne Smith, on behalf of DES ACTION, wrote to the Premier, Mr. Hamer, requesting a deputation to discuss the DES issue.

14th Nov. 1979 Mr. Hamer replied that DES falls within the administration of the Minister of Health, Mr. Borthwick.

11th Dec. 1979 Yvonne wrote to the Minister of Health, Mr. Borthwick requesting a deputation.

13th Feb. 1980 The deputation was finally arranged for 1.30 pm in Mr. Borthwick's office on the 22nd floor of the Health Commission, 'Enterprise House' (!), 555 Collins Street, Melbourne. Thus DES ACTION members - Margaret Goodman, Bon Hull Yvonne Smith and Marian Vickers - met with Mr. Borthwick and doctors from the Health Commission and the Royal Women's Hospital. The meeting lasted 1½ hours; we presented our 'Report on DES' (a short prototype of the DES Fact Sheet); and then left, quite hopeful that some official action would soon be forthcoming on this serious health issue. Included in our submission were the 5 'demands' of DES ACTION:

1. -that all members of the medical profession be alerted and informed of the health risks to DES daughters, sons and mothers. This would mean an extensive educational campaign directed toward all members of the medical profession.
2. -that this campaign also be directed towards the general public so that a register of the Victorian DES population be compiled. A DES register is:
  - a. crucial for the screening and long-term management of DES victims; and
  - b. a necessary preliminary step to future research into the DES syndrome.
3. -that information and screening centres be set up in city, country and regional health facilities.
4. -that funding be made available to publish and distribute informative literature.
5. -that the involvement of DES ACTION in any and all ongoing committees of inquiry and other projects be imperative.

We then went home and waited, and waited. The next meeting of DES ACTION was organized for 12th March. Bon Hull rang Mr. Borthwick's office 4 days before the meeting to see if there was any progress to report.

14th March 1980 Mr. Borthwick wrote pointing out that our 'Report on DES' had appended to it 19 references from literature sources; and he had directed the submission to be thoroughly examined by "people with the proper expertise."

14th April 1980 Marian Vickers, on behalf of DES ACTION, replied that:

- a. -it is 9 years since researchers linked DES-use during pregnancy with cancer in DES daughters.
- b. -there has been no research carried out in Australia.
- c. -there has never been any attempt to alert and warn the public or the medical profession of the health risks associated with DES exposure in utero.
- d. -the information in our report was culled from medical journals which "people with the proper expertise" should already be familiar.
- e. -the 5th demand of DES ACTION was re-emphasized ie. that DES ACTION be involved with any activity.

18th April 1980 Mr. Borthwick acknowledged our letter; the matters raised were being examined; and he would write again as soon as possible.

5th May 1980 Marian wrote to say the next meeting of DES ACTION would be on 24th May; that it was now over 3 months since the deputation and asking whether any progress had been made.

7th May 1980 Mr. Borthwick was seeking urgent advice from the Health Commission so he could advise us of any action being taken.

13th May 1980 Mr. Borthwick again The very detailed report prepared by us was being studied by the Royal Australasian College of Obstetricians & Gynaecologists (RACOG) who had agreed to provide their expert advice. The review of the report by this eminent body would require some reasonable length of time.....

cont'd over leaf.

\* or.... the minister for health re-writes  
gone with the wind!

28th May 1980 A rather sharp letter was written, expressing some of our frustration. It was pointed out that the Australian Drug Evaluation Committee sought the assistance of the RACOG on the DES issue in 1976. Therefore, the RACOG must surely be aware of the issue and all the research cited in the submission. The letter again drew attention to the 5th demand i.e. the involvement of DES ACTION in any and all activity.

4th June 1980 Mr. Borthwick acknowledged the letter; the matters raised were being examined; and he would write again as soon as possible.....

Mid-August 1980 We are still waiting to hear from Mr. Borthwick!!

OVER 6 MONTHS HAVE ELAPSED SINCE OUR DEPUTATION, AND NOTHING HAS HAPPENED .....

# WHAT'S BEING DONE?

in the u.s.a....

On a federal level, the National Cancer Institute finances a major, long-term research program on 3,339 DES daughters in 4 major cities.

In 1978, the Surgeon General of USA issued a 6-page Physicians' Advisory letter to 400,000 doctors on the need for attention to the DES issue, and urging them to notify their patients.

Several states have now passed legislation providing funding for publicity campaigns and the establishment of DES screening clinics.

Funding has also been made available to publish and distribute DES pamphlets and posters to alert and inform the general public of the DES issues.

in australia.....

In Australia NOTHING has been done to alert or assist the DES-exposed.

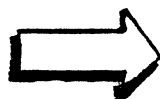
The number of Australian women who were prescribed DES during pregnancy is completely unknown - and there has never been any attempt to find out!

( It is estimated that, in the USA, there are between 6-12 million DES-exposed persons. This includes mothers, sons and daughters; and represents between 2.7 - 5.4 % of the population. )

Consequently, most of Australia's DES population do not know of their exposure; their increased cancer risk; and their need for specialized, long-term screening tests and follow-up care.

in canada....

The following article is from the Herald, 21/8/80:



## Pregnancy drug: New alarm

OTTAWA, Wed. — The Canadian Government today advised women who may have taken the synthetic estrogen hormone drug DES for pregnancy complications in the 1940s and 1950s to get medical examinations for themselves and their children.

DES tablets, prescribed to an unknown number of women to prevent miscarriages, had since been found related to cancer, the Health Department said.

Women who took DES during pregnancy showed a higher incidence than expected of breast cancer and other complications, the department said.

Sons and daughters of women treated with DES had shown "structural abnormalities of the reproductive organs," and daughters had a higher rate of vaginal cancer, it said.



## DES ACTION IN BALLARAT.

Because Senator Jean Melzer (on an earlier visit to Ballarat) had stimulated interest in DES ACTION, she was invited back to speak at a public meeting organized by WEL for the 23rd July 1980.

Jean and Bon Hull were interviewed by a reporter from the Ballarat Courier on the subject of DES and it was demonstrated, once again, how difficult and even unrewarding these occasions can be when the interviewer has no knowledge of the subject. Unless they have first read something of the subject, interviewers seem to develop disbelief as the enormity of the story unfolds.

At the meeting, those present were shown some DES slides on what medical personnel should watch for, and why information should be available and why careful examination should regularly take place. Those attending the meeting appeared very interested in gaining information on DES.

Jean and Bon also talked about the struggle DES ACTION has to gain acceptance and recognition from health providers and administrators at all levels

Among the audience were the parents of two or possibly three DES daughters; and it must again be stressed that few people recognize the equal risk to DES sons. If possible, more meetings in provincial areas should take place. Thank you, Ballarat WEL, for making this one possible.

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Following on from this, another meeting on DES has been arranged by Ballarat WEL. This will take place on: Thursday, 9th October at 8 pm., Ballarat Community Resource Centre, 510 Mair St., Ballarat.

## and in Wangaratta!

DES ACTION member Margaret Goodman has arranged a half-day seminar on DES with the CAE in Wangaratta. This will take place at 1.30-4.30pm Saturday, 4th October.

If you can attend this seminar, or help us organize it, please contact:

DES ACTION  
P.O. Box 282  
Camberwell.3124

## ...FOR YOUR DIARY..

The November meeting of DES ACTION will be held on: Thursday, 20th.

A doctor will speak on the effects of DES on sons. Further details will be given at a later stage. For the moment, keep this evening free-it is your chance to ask questions directly.

SATURDAY 4th. October : CAE Seminar  
on DES in Wangaratta.

THURSDAY 9th. October : W.E.L. meeting  
on DES in Ballarat.

## PLAY IT AGAIN SAM..

### Proluton

The research into the effects of DES-exposure has also cast a dark shadow on all prenatally administered synthetic sex hormones.

We have had many inquiries about progestogenic drugs, eg. Proluton, and have attempted to find out more on this topic.

Unfortunately, to no avail.

We will keep you informed of our progress, but at the moment the subject appears to be a "closed shop" with the medical profession.



# HIT. . . .

We know now that the fact that DES was administered was a mistake, and it caused a very serious accident. When there is a car accident, everyone is agreed that it is very important to stop and render assistance after the accident. Now what worries me is that the DES story seems like a HIT & RUN accident.

A friend of mine was involved in an accident recently. She was quietly driving along when she was suddenly hit by a big truck (maybe something like the big drug companies that don't want to know about their mistakes; or perhaps our big government institutions that don't seem to be doing much at the moment). Anyway, this huge truck smashed into my friend's little car, sent her spinning into the curb, and then just drove off regardless.

A little dazed and confused, my friend was attempting to take down the fellow's number when a passerby, who had seen the whole incident, stopped and handed her his business card saying: "Call on me anytime."

DES ACTION needs people like this - supportive, informed witnesses. There are probably a lot of people in the community who could come forward, give evidence and render some assistance after this DES accident.

Just then a motorcyclist stopped and asked: "Would you like me to chase after the truck driver and bring him back?" This was a very kind offer, which was gratefully accepted. When the motorcyclist returned he reported that he'd had some trouble persuading the truck driver but, yes, he was returning.

We do need people who are ready to take some individual action - to help collect information and go after the assistance we need.

When the truck driver finally reappeared, he roundly abused my friend. He said he was not aware of hitting her car and, furthermore, he did not have time to waste like this as he was running late as it was. Anyway, what did she have to complain about? She wasn't dead, or even seriously hurt!! He saw really serious accidents everyday; and she should count her blessings.

Does any of this sound vaguely familiar to DES victims?

At the insistence of the witnesses, the truck driver reluctantly gave a name and address. HOWEVER ALL LATER ATTEMPTS TO CONTACT HIM FAILED!!

DES ACTION asks that the principle of rendering assistance after an accident be upheld. We want the risks and damages of DES recognized and widely acknowledged SO THIS WILL NEVER HAPPEN AGAIN.

And is this the end?  
Just another hit-and-run?  
Not quite.

From the house opposite came the welcome offer of practical help - the use of the telephone and: "What about a cup of tea while you wait?" The woman who lived there just happened to be home, off work, recovering after a car accident!

DES ACTION is a support group - as a DES mother, daughter or son you have something useful to contribute: your own experience. DES ACTION needs your support.

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.....  
Help DES ACTION take action  
.....  
.....

# AND RUN

by Beryl  
Pausacker

# GOVERNMENT RESPONSIBILITY & DES.

by  
Freeholder\* Joan Steinacker.

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(\* A Freeholder is an elected member of a county board, involved at the municipal level. )

This article is reprinted from DES ACTION VOICE, a publication of DES ACTION/National, U.S.A.

The thoughts expressed and the issues raised are very relevant to the situation in Australia.  
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I suppose we are as well protected against troublesome materials as any people on earth. The Congress has recognized the obligation of the government to protect the people against foods and drugs that would have long-term deleterious effects upon the human body. Over the years highly restrictive laws have been enacted - all with the objective of protecting the people against dangerous substances.

Yet, for thirty years, from 1941 to 1971 our government tolerated DES (diethylstilbestrol).

The subject is of special interest to me because I am personally involved. My physician prescribed DES for me and now my daughter does have problems. The watch will go on, and on, year in and year out.

I am a politician and a public official, part of the system and, as such, I am part of the structure that allowed this to happen to myself, to my daughter and to millions of others. The government failed us, and I believe the government has some obligation to all of us as a result of the failure.

Apologies from the Food and Drug Administration are not enough. Mea Culpas from the scientific communities are not enough. Excuse me's from the drug industry are not enough.

There are two things I want from the government in relationship to DES and I am committed to working for both for as long and as hard as it takes.

First, from personal experience, I can tell you that the costs we are now experiencing in my own family to

keep my daughter under the kind of attention that is needed are excessive. If problems are detected at some time in the future and more remedial medical action is required, I have no idea what the cost might be. I am not talking here about the worry, the sense of uncertainty or any of the other psychological mal effects this experience has had on my family and on so many thousands of others, but just about the actual cost in real dollars. And yet, the government has felt no compulsion to help any of us. I think that is wrong. The government failed us, failed to warn us against DES, failed to protect us, and we had a right to expect that degree of protection.

In my judgement, the medical cost to parents and to children who are victims of DES should be borne through some governmental funding mechanism. Millions upon millions of dollars are being wasted every year for foolish programs, and we all know it. Yet, the thousands of families who were victimized by the government's failure in the DES case are not helped. It is a disgrace and those medical bills that are directly related to DES should be paid for through a special governmental program, and no one can convince me otherwise.

This generous government of ours, which has chosen from time to time to feed the people of the world, has turned its back upon so many of its own, and it is time we put that situation to rights. Payment of DES-related bills ought to be a federal responsibility.

And, there is the other thing I want to see as a result of my own experience. We need laws and we need enforcement that will guarantee that there will never again be another DES situation for so long as this nation exists. When we turn on our tap, we have to have confidence that the water is clean. When a physician prescribes a medication, we must be able to have confidence that the capsule contains no poisons that will damage our offspring.

I do not regard this as a woman's issue. It is a human issue. It is a question of right.