THE DES ACTION
VOICE
A FOCUS ON DIETHYLSTILBESTROL
Fall 1990 #46

DESAD Update

from the DESAD Project, Mayo Clinic

DES-Exposed Daughters

This year there is little new to report. Women exposed before birth to DES continue to show an excess in the occurrence of cervical and vaginal dysplasia when compared to unexposed controls. However, as long as DES-exposed women continue to have annual examinations and pap smears, it is possible to diagnose these conditions early, in most cases, and often treat them in the office.

Infertility remains an important problem for many DES-exposed women. If it has not been possible for you to become pregnant, we strongly suggest that you seek the advice of a subspecialist in reproductive endocrinology. In some cases, DES-exposed women who have not been able to conceive on their own have achieved successful pregnancy through advanced reproductive technology (gamete intrafallopian transfer—GIFT—and in-vitro fertilization procedures).

"Women exposed before birth to DES continue to show an excess in the occurrence of cervical and vaginal dysplasia when compared to unexposed controls."

DES-Exposed Mothers

The DES Mothers Breast Cancer Study has not published a report during the past year. However, preliminary information suggests that there has not been a dramatic increase in breast cancer cases. Because DES mothers are all in the age group during which breast cancer occurs frequently, we continue to advise them to have mammography once a year.

DES-Exposed Sons

There have been no new reports on DES-exposed sons during the past year.

INSIDE

Miss Texas 1990: A DES Daughter

Suzanne Lawrence, 1990's Miss Texas, is a DES daughter and cancer survivor who uses her high profile position to speak out about DES and cancer.

The 21-year-old founded "Smiles Against Cancer" in her hometown of Humble, Texas, as a support group for cancer patients and their families. Smiles Against Cancer provides hope and laughter as well as support and understanding. Lawrence won a $10,000 "Quality of Life" scholarship award at the Miss America pageant in September for her volunteer work.

Suzanne Lawrence helps validate others' experiences when she

talks about her DES exposure. It's heartening to see beauty pageant contestants talk about issues of concern to women's health and survival. DES Action salutes Suzanne Lawrence.

Get Into Action

DES Action USA could not have originated and grown without the dedicated efforts of volunteers. Each group was created and nurtured by volunteers. *We still need you.* Write your group today. Offer your services for a few hours a week. Become a part of the action with DES Action.

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letters to the editor

Dear Editor:

This might be of interest for VOICE readers. Susan Bell's doctoral dissertation, The Synthetic Compound Diethylstilbestrol (DES) 1938-1941: The Social Construction of a Medical Treatment, is available in paperback from University Microfilms International, 300 N. Zeeb Road, Ann Arbor, Michigan 48106. The telephone number is 1-800-521-0600 or 313-761-4700, and the cost is $25 or $35. I have read my share of dissertations and hers is very readable.

M.R.

Dear Editor:

I am a DES daughter with a cauterized cervix that is beyond incompetent. My husband and I have suffered four pregnancy losses, two due to premature labor (our first daughter lived for one hour; her sister for three). We were advised by the perinatologist at our HMO that nothing further could be done.

Upon further investigation, we learned that I could be a candidate for a transabdominal cerclage, a procedure performed by Dr. Julian Parer at U.C. Medical Center in San Francisco. Upon meeting with Dr. Parer, our skepticism was overcome by his astonishing track record for this surgery: 18 for 18 (we will be #20 out of 20). These numbers are even more amazing when one considers the stringent eligibility

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VOICE

Preventing Drug-Induced Disorders

Paul W.J. Peters, Prof. of Teratology, State University of Utrecht, the Netherlands
Director, International Centre for Birth Defects, Bergen, Norway

This is a summary of Peters' address to the Symposium, 3rd DES European Conference, Dublin, Ireland, 14 September, 1990.

Toxicology, the study of poisonous substances, recognizes several disciplines such as carcinogenicity (substances causing cancer), mutagenicity (substances causing changes in genes or chromosomes that can be inherited), and reproductive toxicity. Reproductive toxicology is concerned with possible effects of substances on the reproductive process, i.e. on sexual organs and functions, endocrine regulation, fertilization, transport of the fertilized ovum, implantation, and embryonic and fetal development.

Some developmental disorders can be prevented by avoiding exposure to microorganisms or chemicals, including drugs, that cause such disorders. This is not only important for physicians prescribing drugs, midwives monitoring pregnancies, and public health officers, but especially for parents taking on the responsibility of having a baby.

Knowledge of the different pre- and post-natal developmental stages and the reproductive cycle is essential to understand this statement. The basic principle in reproductive toxicology and malformations is that the response of a fetus depends upon the nature and the dosage of the substance, the stage of development of the embryo/fetus and its genetic makeup. Chemical agents of different natures can induce developmental disorders either via the mother or via the father. The common idea that only the first trimester of pregnancy is the vulnerable stage of development is not correct. From the formation of the egg and the sperm to at least the first years of life the developing organism is susceptible to the harmful effects of chemical agents.

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Developmental disorders include not only malformations visible at birth, but also spontaneous abortions, fetal death, and functional defects including behavioral defects. Studies both in the human and in laboratory animals make it possible to select substances to avoid exposure to developmental toxicants which are already on the market or still under development. For parents, midwives, physicians and those concerned with primary prevention of developmental disorders, a useful slogan might be: "How to make a healthy baby?"

The approach for primary prevention in this respect is most successful if a chemical is identified as harmful to reproduction. When thalidomide was recognized as the causal factor in an epidemic of limb defects, removal of the drug from the markets resulted in a dramatic disappearance of these defects. This event was also accompanied by a drastic avoidance of general drug intake by pregnant women. Nowadays, however, there are indications that about 80 percent of pregnant women use prescribed or 'over-the-counter' drugs. There can be no reasonable doubt that drugs are often more widely used in pregnancy than is justifiable from the knowledge available. This may be one aspect of what is sometimes called the medicalisation of pregnancy. At times it may even seem that pregnancy is to be regarded as dangerous until proven safe, whereas drugs are regarded as safe in pregnancy until proven dangerous.

Health care professionals, and also pregnant women, need to develop a more critical attitude to the use of drugs during pregnancy, or better still to the use of drugs during the fertile period, using them only when they are essential and thereby avoiding many unnecessary and unknown risks. The same applies obviously for social drugs like tobacco, alcohol and addictive drugs.

Health professionals and patients need to be informed about proven safe drugs. Since 1984 classification systems have been introduced in the U.S.A., Sweden, and recently also in Australia. These systems allow a general estimation of the safety of drugs in pregnancy and with

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respect to reproduction. In the European Community a draft proposal for categorization has been prepared, but in 1990 not yet accepted, that is based on the fact that there are human data available.

Categories to be used for labelling of medicinal products for their use before and during pregnancy, and during lactation under "Precautions."

CATEGORY A:

This medicinal product has been used by a large number of pregnant women. No harmful effects are known with respect to the course of pregnancy and the health of the unborn and the newborn.

CATEGORY B:

Medicinal products for which insufficient human data are available to evaluate the safety with respect to the course of pregnancy and the health of the unborn and the newborn.

"For parents...a useful slogan might be: 'How to make a healthy baby?' "

B-1 The safety of this medicinal product for use in human pregnancy has not been established. An evaluation of experimental animal studies does not indicate direct or indirect harmful effects with respect to reproduction, development of the embryo or fetus, the course of gestation and pre and post natal development.

B-2 The safety of this medicinal product for use in human pregnancy has not been established. Experimental animal studies are insufficient to evaluate the safety with respect to reproduction, development of the embryo or fetus, the course of gestation and pre and post natal development.

B-3 The safety of this medicinal product for use in human pregnancy has not been established. Evaluation of experimental animal studies has shown the product to be harmful to reproduction.

CATEGORY C:

This medicinal product does not increase the spontaneous incidence of human developmental disorders, but has effects with respect to reproduction, on the unborn or the newborn.

CATEGORY D:

This medicinal product is suspected to increase the spontaneous incidence of human developmental disorders in the embryo or the fetus.

CATEGORY X:

This medicinal product is known to cause human development disorders.

Knowledge about the (un)safety of the drug in the human is thus the starting point. All aspects of reproduction are taken into consideration (that is, from the formation of the egg and sperm until birth) for chemical exposure and from the formation of primordial cells until the final organ differentiation to detect prenatally induced effects. The term 'pregnancy' concerns the whole period of pregnancy, including the period in which no certainty about a pregnancy exists. This implies that drugs should always be prescribed to fertile women according to the classification system.

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Over the years many people have contributed memorial gifts to DES Action or honored special events with a donation. Now DES Action has produced new cards for our Tribute Gift Program. You can honor a friend or relative for an anniversary, a birthday, as a memorial donation, or for any important occasion, by giving to DES Action in your honoree's name. We will acknowledge the gift to both the donor and the honoree. One member reports that she plans to hand our Tribute Gift cards to her friends this holiday season and ask that they contribute to DES Action instead of buying her presents. The Tribute Gift Program is a meaningful way to honor an important person in your life and to help DES Action at the same time.

If you would like to receive our Tribute Gift cards please send us a note or call to let us know how many you would like. We will send them right away.

On the Legislative Trail

In the major states of Pennsylvania and California, DES Action members have recently testified in their state legislatures against bills supported by manufacturers, particularly drug companies, that would severely damage consumer rights. Sue Lawler, coordinator of DES Action/Penn., spoke to a State Senate committee about a bill that would limit the rights of Pennsylvanians to collect damages from manufacturers in cases involving fraud, misrepresentation, implied warranties, malfunction and negligence.

"DES mothers, daughters and sons number 650,000 in Pennsylvania. Increased medical costs, infertility work-ups, high risk pregnancy care, intensive care neo-natal nursery, are part of being DES exposed. Under our current product liability laws, DES litigation is difficult. With the passage of House Bill 916, it will be impossible for any victim of DES to sue the manufacturer.

It is not possible to know when the DES legacy will end. But we do know when it began and the manufacturers must be held accountable. If we adopt tort "reform" we disregard all affected by dangerous products, including the DES-exposed. DES has drastically altered our lives. The manufacturer would not have a liability had proper testing been done before marketing. If we approve tort "reform" then we open doors and make way for more dangerous products. We as consumers cannot afford to continue to suffer the harmful effects of both dangerous products and ill-conceived legislation.

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DES has been an expensive lesson. We as victims should not be solely responsible for paying the costs. We must maintain our current product liability laws. In doing so we maintain high product standards; promote careful testing of new products; discourage and avoid the repetition of a DES tragedy."

After testimony from Ms Lawler and other consumer groups, the committee decided to postpone a decision on the bill until November. Meanwhile, Pennsylvania members of DES action are letting their State Senators know what they think about HB 916.

In California, drug companies wanted to pass a bill that would exempt them from punitive damages if the product had prior approval from the Food and Drug Administration. Since punitive damages are what makes it possible for lawyers to take cases, far fewer suits could be brought if this bill passed.

Executive Director Nora Cody told the state Assembly Committee hearing this bill, "DES daughters sue because no one, not you and certainly not the FDA, has been able to prevent deadly drugs and devices from flooding the marketplace. Certainly not only the DES story, but the sad cases of Oraflex, Zomax, the Dalkon Shield, and other IUDs—all these have shown us that we can't rely on the drug companies to produce full and complete information to the FDA. Neither can we rely on the FDA to take swift and decisive action to stop bad drugs from reaching consumers.

How can we contemplate loosening product liability restrictions, after all of the tragic drugs we hear about, and when we know the FDA has been weakened and made less effective? What other check is there today on the corporations that create and promote the Dalkon Shields and the DESes? We know that some bad drugs and devices will get on the market—the worst part of this bill is that it removes the incentive for the drug companies to take them off, even after they begin injuring consumers. As to the claim that this bill will help encourage research into new drugs: no ethical drug company that carefully tests its products has anything to fear from current product liability law in California.

You, as our representatives, are being asked to vote away an important legal right, and we get nothing in return. I ask you to help us keep our rights and oppose SB 1210."

A happy ending—the committee vote against the bill was 4-1.

VOICE

We Are Not Alone

One of the central themes of the 3rd European DES Action Conference in Dublin this September was working together on our common concerns. The experiences of DES Action USA in doing public education, contacts with the medical and research communities, and working with the government are useful for the newer DES Action groups.

Sharing is not a one-way street, however, because our European colleagues help us by getting major attention to DES on an international level through the European Parliament. This is more than a paper group. It represents the 12 members of the European Economic Community (EEC) who in 1992 will become one huge market area of 320 million people. Thus, declarations by this Parliament carry weight and can lead to worldwide attention to DES and perhaps a ban on its use anywhere.

DES was used for pregnancy problems in the Netherlands until 1975 and in France until 1977, even though the link to cancer was reported in the U.S. in April 1971 and the FDA issued its warning in November 1971. It is still being exported and taken by pregnant women in third world countries. It will take worldwide pressure and cries of outrage to stop this tragic practice of "dumping" dangerous drugs in the Third World.

Finding out just how extensively DES was used, and planning for public and health provider education, are the objects of this Resolution that originated with our DES Action group in the Netherlands and that was passed by the European Parliament in 1989.

RESOLUTION
on the use of diethylstilbestrol (DES) and the effects on the health of users and their children.

The European Parliament,

- having regard to the motion for a resolution by Mrs. van Dijk on the use of diethylstilbestrol (DES) and the effects on the health of users and their children (Doc. B2-1242/87),
- having regard to the Council directive (1981) which prohibits the use of DES for animals because of its harmful effects,
- having regard to the fact that in Greece the use of DES is solely restricted to the treatment of prostate cancer since 1980,
- having regard to the prohibition imposed by many Western countries since 1975 on the use of DES to treat threatened miscarriage, because of the increased risks for the mother and child, and because treatment with DES was never proved to have been effective against miscarriages,
- having regard to the report of the Committee on the Environment, Public Health and Consumer Protection (Doc. A2-70/89)

A. whereas the pharmaceutical industry still markets DES under various trade names for veterinary and other uses,

B. having regard to the proven harmful effects of DES when used during pregnancy to prevent threatened miscarriage, namely:

DES daughters have an increased risk of cancer of the vagina and/or cervix and are more likely to have fertility and pregnancy problems,

DES mothers are more likely to develop breast cancer,

DES sons are more likely to suffer from fertility problems due to low sperm count,

"It will take worldwide pressure and cries of outrage to stop this tragic practice of 'dumping' dangerous drugs in the Third World."

C. whereas in the past DES has, in addition to these uses, also been used for a variety of other indications,

D. whereas DES is still used in the Community for various applications,

E. whereas DES is also exported from the Community to third world countries and whereas it is not clear how it is used in those countries,

F. whereas discussions and publications in the medical profession are again considering the long term use of DES for women to prevent osteoporosis during menopause,

G. whereas the effects of DES only become apparent at a later stage and whereas only in the Netherlands is DES recognized to be a serious problem, mainly as a result of the activities of the victims themselves,

H. whereas in countries such as France, Spain, Portugal, Ireland, United Kingdom and Belgium it has recently become apparent that women have

suffered as a result of using DES but, as in other Community countries, the problem is denied by the medical profession,

I. whereas many women who might have been exposed to DES find it difficult to, or are no longer able to, establish this link, as medical records have often been destroyed,

J. whereas it is to be feared that women (in unknown numbers) have come into contact with DES in all countries of the Community, but figures are being quoted, on the basis of estimates, for one Member State alone and cannot provide a reliable indication,

K. whereas in some Member States even information for doctors on the effects of the use of DES is clearly inadequate, and whereas symptoms are wrongly interpreted and as a result unnecessary, sometimes even harmful, treatments are used,

L. whereas research into the effects of the use of DES on the third generation has not yet produced any reliable findings,

1. Notes that:

a. up to now in Europe, unlike

the USA, far too little attention has been paid to the extensive DES problem;

b. DES has produced many more victims than is generally known at present;

c. medicine now only requires the production of decreasing quantities of the DES hormone, which has been used in the past to treat cancer of the prostate, since for new cases alternative medical products are available including other estrogens;

2. Calls on the Commission:

a. to ascertain:

❦ which firms are or have been involved in the manufacture and/or export of DES;

❦ the names under which DES was or still is being marketed in the countries of the European Community;

❦ the countries to which DES is exported;

❦ in which Member States DES is authorized on a national basis and for which indications;

b. to report to the European Parliament on these investigations,

c. to set up a central registry for research on hormonal transplacental carcinogenesis in Europe,

d. to initiate an information campaign to make the public, those affected, and the medical profession aware of the effects of the use of DES,

e. to set up an investigation, on the basis of the remaining medical records, to trace those exposed to DES since 1947 and to conduct other active enquiries in order to document the size of the problem in Europe, so that appropriate action may be taken and all those affected given proper treatment;

3. Instructs its President to forward this resolution to the Council, the Commission and the governments of the Member States. ❦

letters to the editor

LETTERS *from page 2...*
criteria: in order to even qualify for this surgery, a woman has to have had at least two failed vaginal cerclages. Because of my age—pushing 40—and number of losses, Dr. Parer was willing to accept me as a patient even though I had "only" had one unsuccessful vaginal cerclage.

My lay-person's understanding is that the surgery is not all that technically complicated, just rare. Rather than stitching up the bottom of the cervix by going in vaginally (with accompanying risk of introducing infection), a vertical abdominal incision is used to place a stitch(es) at the top of the cervix, by the uterus. I tend to think of this as the medical equivalent of building a retaining wall. The surgery is performed at around 14 weeks so that one is fairly certain of a viable pregnancy, as the stitch is permanent and delivery must by by C-section. Although the only real danger (besides normal surgical risks) seems to be blood loss during the operation, it is major surgery and I recovered only in time for bed rest at twenty weeks.

I have finally let our friends proceed with planning the baby shower they have been trying to throw for us for 6-1/2 years. I am also learning to say "when" and not "if" without feeling like I am tempting fate. As I have received such tremendous medical care and abundant emotional support from my two physicians, I wanted other DES daughters with incompetent cervices to know that there may be something else out there for them. It's starting to feel like it may all have been worth it.

D.W.

P.S. It's a girl!—September 20.

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