

T H E D E S A C T I O N V O I C E

A F O C U S O N D I E T H Y L S T I L B E S T R O L

Winter 1994

#59

Long Term Emotional Effects of DES

by Roberta Apfel M.D.

(Dr. Apfel's comments were part of a presentation on DES reported in the *Journal of Psychosomatic Obstetrics and Gynaecology*, 14, 1993, "Effects of diethylstilbestrol medication during pregnancy: report from a symposium at the 10th International Congress of International Society of Psychosomatic Obstetrics & Gynaecology").

DES can be seen as a paradigm of dilemmas of modern medicine, the wonder drug we should wonder about. The story of DES is the story of the tension in twentieth century medicine between, on the one hand, activity to do good—using technology and advances—and medical grandiosity, and, on the other hand, passively letting nature takes its course. If we can learn from this historical mistake and forge a new collaboration of professionals and consumers, we can truly make progress. If we do not learn, we will only repeat the

"The emotions are invisible. The injuries from DES are not obvious to others, so there is no shield of protection in social encounters."

mistake and see the same widespread use of doubtful medication—of other estrogens for instance—with dire consequences.

DES created an emotional trauma for everyone involved: the mothers who took it, the female offspring, who were exposed, the grandchildren perhaps. The DES experience has been traumatic also for those we know less about: the fathers, the sons, even the physicians, those responsible in the drug companies, and the officials in the regulatory agencies. It was and is a public scandal about the most private areas of life. Mothers suffer with guilt, self-blame and anxiety over the time bomb effects for their offspring. Daughters suffer with the pain of infertility, fear of cancer and premature death, fear of pregnancy problems, fear for their children,

difficulty trusting their doctors, and rage at drug companies.

Doctors hate to make mistakes. They live in a culture, where both acknowledging and not acknowledging mistakes have huge consequences. Many of them have refused to provide the information necessary for tracing DES-related disease. The DES story touches close to home—many of the pregnant women who were prescribed DES were doctors' family members and friends.

DES' harmful effects were a disruption of what was expected. At the first discovery, the emotional impact is felt with shock and disbelief, a sense of betrayal which is renewed with each new discovery of medical disasters. The emotions are invisible. The injuries from DES are not obvious to others, so there is no shield of protection in social encounters. This compacts the sense of loss and pain for the injured. In particular, the doctors' silence has exaggerated an emotional trauma for everybody concerned....

In two kinds of relationships where trust is much needed, the DES experience has threatened trust: between mothers and daughters, and between patients and physicians. The reactions to the harmful effects of DES medication during pregnancy have

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✉ letters to the editor

Dear Editor:

I am 40 years old, a lesbian, and a DES daughter who has been experiencing sporadic symptoms of menopause over the past year and a half. I am hoping to start an informal discussion group of DES-exposed women, regardless of sexual preference, who may be grappling with their own symptoms and/or decisions related to treatment, including HRT.

If you are interested in meeting approximately once a month in a San Francisco/Bay Area location to share insights, medical knowledge/experience with alternative therapies, and general support around menopause, aging, and health care, I would welcome hearing from you.

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(415) 777-8889 (days)
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Confidentiality Assured

As a courtesy to our members, it is our policy that we never sell or rent your names and addresses to any other organization.

Next time you decide to honor someone with a gift or memorial tribute, think of DES Action. Our **Tribute Gift** program allows you to donate in someone's honor or memory.

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Notes From Nora

We don't often profile individuals in these pages. But I'm so excited about Jean Golomb and her work—which can serve as a model for other states—that I just have to tell you about what she's doing in Pennsylvania.

On October 20 the Speaker of the Senate of Pennsylvania introduced Senate Bill 1396: the "Diethylstilbestrol Public Information and Education Act." The bill was simultaneously introduced in the House as House Bill 2244. This achievement is due, to a great extent, to the tireless work and perseverance of Mary Jean Greco Golomb.

Here's a quote from Jean's outreach letter about the bill:

"It's been a long, hard struggle, but we're finally making some headway.

After 50 years of inactivity, Pennsylvania has taken the first step toward helping 480,000 victims of diethylstilbestrol (DES) who live in our state...

Senate Bill 1396 and House Bill 2244 will provide for public information and education on DES in the Department of Health, create regional screening centers and a registry of victims, provide for education of health care providers and will make it impossible for insurance carriers to cancel policies for DES victims."

Jean is now carrying out an aggressive campaign to win support from both individuals and organizations for the bill. If you are a Pennsylvania resident, please write **today** to your State Senator and Assembly person in support of this bill. If you are a member of another group—a

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church group, PTA, political or civic organization—see if your group will write a letter of sup-

APFEL from page 1...

demonstrated that when iatrogenic disease occurs, one possible road to healing and secondary prevention is political action by the victims.

Knowledge helps for DES daughters, DES sons and DES mothers and should be provided for exposed offspring consistent with their age and stage of maturity. Chances to talk between generations and individually, and regular medical surveillance with a competent caretaker, are good supports. Political activity is especially valuable as it informs and also reduces a sense of helplessness. Law suits have not been very healing; even large financial settlements do not repair all that has been lost. But



Jean Golomb

port. Send copies to Jean at DES Action PA, P.O. Box 286, Nescopeck, PA, 18635-0286. 🐾

***"...the DES
experience has
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between patients
and physicians."***

also medical professionals need to face the harm caused by the use of DES as a medication for pregnant women. Doctors need to deal, personally and within the profession, with medical mistakes as they are made, and not compound mistakes and losses by abandoning patients. 🐾

Remembering DES: An Interview with a Pharmacist

by Marie-Louise Gariepy, DES Action Canada Newsletter Issue 35

Somewhere between the patient and the doctor, somewhere between the patient and the pharmaceutical company, is the pharmacist. Very little has been said about the link between DES and the pharmacists who dispensed this drug. What do they think about the DES story, those men and women who actually placed this bogus "miracle drug" into the hands of women who were prescribed DES?

There were some pharmacists who suspected the safety and effectiveness of DES from the beginning. Mr. Saul Cape is one of these people. A pharmacist since 1936, he remembers the DES story well. Today, many years later, he candidly describes his views about the popularity of DES, which peaked during the 1950's, as well as some of his opinions on the practice of medicine and pharmacology.

DES Action: What do you remember about DES?

Mr. Cape: Diethylstilbestrol was brought over from England for the treatment of advanced forms of prostate cancer. In those days, estrogens were just starting to come into the forefront in the drug business. They started to be used in the late 1930's and early 1940's. DES was a new estrogen and doctors assumed that it could be used to treat a variety of gynecological problems. That was the mentality at the time. (see box).

DES Action: What were the doctors' attitudes at the time that

DES appeared on the market?

Mr. Cape: In my opinion, the doctors that prescribed DES were not responsible enough in investigating what diethylstilbestrol was composed of and what the side effects were. At my pharmacy, we received many complaints of the drug's side effects and gave that information to several doctors.

DES Action: What side effects did you hear about?

Mr. Cape: Nausea, vomiting, headaches, dizziness. Women

had problems with their vision and intestinal problems. DES is absorbed directly by the stomach and then passes to the liver where it is digested and eliminated. Anything that goes into the liver is a potentially dangerous drug and can have repercussions on the entire body. But nobody took this into consideration or bothered to investigate the side effects (that were being reported) until 20 years later when cancer started to occur in the children. They never knew just how dangerous it was until then.

DES Action: What dosages of DES were prescribed?

Mr. Cape: The most commonly prescribed was the 5 mg. pill. There were 1 mg., 2 mg. and 5 mg. pills. A doctor prescribed two, sometimes three, pills per day and told the patient to check back in a couple of weeks. In the meantime, a patient would often return to the pharmacy a few days later complaining of dizziness and nausea. I would tell her to stop taking the drug immediately and to call her doctor.

DES Action: When was DES most widely used?

Mr. Cape: It was most prolific during the 1950's. By 1965, its use had diminished considerably and by the early 1970's medical researchers and the government became aware of the effects of DES on children exposed to it. I was a pharmacist in a hospital from 1960—1983. I told the doctors that we shouldn't use diethylstilbestrol.

"One of the uses which DES was approved for by the U.S. Food and Drug Administration in 1941 was for the treatment of prostate cancer. DES initially proved life-prolonging for advanced cases of prostate cancer by suppressing the male hormone, testosterone, which stimulated tumor growth. Unfortunate side effects included feminization of the male and an increased risk of male breast cancer. However, DES is still currently on the market for the treatment of advanced breast and prostate cancer. For women, the initially approved uses of DES included the treatment of "menopausal symptoms", gonorrheal vaginitis, and the suppression of lactation. DES was never officially approved for any use during pregnancy."

—Apfel, Roberta, and Fisher, Susan, *To Do No Harm: DES and the Dilemmas of Modern Medicine*. Yale University Press, 1984, p. 19.

DES Action: How much DES was prescribed and where was it used the most?

Mr. Cape: It is hard to say, but DES was used in Montreal a lot. It was very popular.

DES Action: What about the role of the pharmaceutical companies?

Mr. Cape: Pharmaceutical companies do not sufficiently test their drugs; they put their products on the market too soon and ask too much money for them. As soon as they discover a product that helps a few people, they assume that it will save the entire world. But people are different, their systems don't function the same way. You can't treat every woman with the same drug.

Drugs should be tested for a period of at least five to ten years. DES is not like insulin. We know that insulin helps diabetics, it saves their lives. But these hormones, these estrogens, are touch and go.

DES Action: What do you think about doctors today?

Mr. Cape: Doctors are a bit more careful today, but not as careful as they should be. They are so inundated with patients...they often don't have time to investigate a drug, to read about it, to find out what it is made of and what its effects are. The pharmaceutical companies have a product to sell so they stress only the positive aspects of a drug to the doctors. This is exactly how DES was introduced.

DES Action: What about the government?

Mr. Cape: Unfortunately, the government claims that it has no money. Their laboratories have 8 employees or less to test thousands of drugs. It takes years to

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research a drug properly. That's our big problem: the government doesn't have adequate facilities to test drugs. And the powerful pharmaceutical companies exert pressure on the government to have new drugs approved.

DES Action: And the pharmacist in all this?

Mr. Cape: The pharmacist is

merely a link between patient and doctor. Doctors may prescribe to patients whatever they wish. However, as a pharmacist, I have the right to refuse to provide a drug to a particular client if I believe it is contraindicated for him or her.

I read about drugs in specialized medical journals and drug manuals so that when a drug is found to be ineffective or dangerous, I'll know about it. Drugs can be very dangerous if they aren't given, and taken, with care. And that's what a druggist is for—to watch the patient, and watch the drugs.



DES: Still in Use

DES is still being prescribed—and sold over the counter—to women in developing countries. DES Action the Netherlands brought new evidence of this disturbing fact back from the 7th International Women and Health Conference held in Uganda in September 1993. Women from Uganda, Nigeria, Ghana, South Africa, Mexico and Colombia testified that DES is still used in their countries to suppress lactation and/or to prevent miscarriage. DES is especially commonly used to suppress lactation in

Africa. Women are often talked into giving their babies formula instead of breast milk and use DES to stop lactation.

DES is still on the market in many countries because one indication remains accepted by doctors, the treatment of prostate cancer. However, even this use is questionable. DES is no longer considered the drug of first choice as it causes more severe side effects than other estrogens. It is sad that DES continues to be used by women despite the many years of evidence of inefficacy and carcinogenicity.

Check Up for Your Health Care

by Andrea Goldstein, Vice-Pres., DES Action

ASSERT v. 1. to maintain or defend (claims, rights, etc.) 2. to put oneself forward boldly and insistently.

The nation today finds itself at a crossroads in terms of providing health care for its citizens. Of late I have found myself feeling anxious about the type of care all of us might find ourselves forced into using. Never has there been a better time for each of us to work on becoming more assertive as health care consumers, for doing so may make the difference between receiving good or less than good care. For some, it could mean the difference between life and death.

Several years ago the *Voice* published an article I wrote entitled "How to get the best medical care" (Issue 37). I currently sit on a Professional Education Committee overseeing a CDC grant on breast and cervical cancer screening guidelines. The stories I have heard at these meetings compel me to revisit this issue.

Most of us take on faith that we receive quality health care from an unbiased physician. There is a lot of talk today about the over-use of diagnostic tests. Yet did you know that in some HMOs (Health Maintenance Organizations, or, pre-paid health plans), doctors are paid according to how great a profit is made by the facility? There is a lot of talk today about how we must find a way to limit medical mal-practice litigation. Should we be denied this vehicle if one of these same cost-cutting doctors overlooks something that imperils our health? Did you know that there are vast

differences in the quality of services provided by laboratory facilities but that, regardless of where the physician would like to send specimens for examination, the patient's insurance coverage often dictates where these specimens are sent? Did you know that for some patients with breast cancer, lumpectomy and radiation is appropriate, yet mastectomy is often held out as the only option in certain HMOs because it is cheaper?

Here are some things to think about before your next trip to the doctor.

Are you joining an HMO? Is it closed, meaning all care is provided at specific sites, or can you choose from among a list of physicians in different areas? Are your current physicians a part of the plan or will you have to start over with new doctors? If so, check them out! How does the practice run? Is it solo or group? Do you have to see a primary care doctor or nurse practitioner before you can be referred? How do you feel about any possible restrictions?

It is crucial to understand your coverage. Yet it is also true that many people do not. I spent 13 years working in the health care field. Part of that time was spent explaining benefits to patients who had no idea of what was covered under their plan. Orientation meetings and information packets are worthless if not utilized.

If you are a DES daughter, you know that infertility is a major concern for many of us. THINK. If you can only use certain doctors within the plan, see if that person is an ob/gyn doing infertility or a

"Here are some things to think about before your next trip to the doctor."

bonafide infertility specialist. There IS a difference. A bargain isn't a bargain if you have to pay out of pocket to see a specialist who is not on your plan.

Check on the lab. Are specimens analyzed in-house or elsewhere? What quality control methods are employed? Who is reading the slides? How many slides are read by one technician in a day? You may be surprised to learn that some labs allow very little time for readings because of the volume they want to cover.

What about hospital affiliations? Is there a neonatal intensive care unit? Who are the other specialists affiliated with your plan whom you might see if a serious problem arises? Can you be referred to a large teaching hospital for treatment and care?

The idea here is to provoke thought. Even if you are already in a good plan, are you using it to your advantage? Have you thought about all the points listed above? Have they made you think of other questions?

Make informed choices. Take responsibility. See to it that you come for a medical visit prepared with questions and concerns. Put yourself forward boldly and insistently. Isn't it time you gave your doctor's performance and health care plan a check-up? 🐾



Surgery for a T-uterus?

by Pat Cody

With the cautionary title, "Hysteroscopic metroplasty in the diethylstilbestrol-exposed uterus and similar nonfusion anomalies: effects on subsequent reproductive performance; a preliminary report", Drs. Theodore Nagel and John Malo of the Dept. of Ob/Gyn, University of Minnesota in Minneapolis, report* on surgery they performed on eight women, five of whom were known DES daughters. Five of these eight patients had histories of pregnancy losses and the other three presented for infertility. The procedure including removing tissue inside the uterus to arrive at a smoother uterine contour.

In all cases the surgery created uteri that were "more normal in appearance," and four of the eight women (two DES daughters and two non-DES exposed) had successful pregnancies. The DES

daughters were not without problems: one required a cerclage and medication to prevent premature labor, and the second delivered at 25 weeks; the infant at the time of the article was 9 months old and doing well.

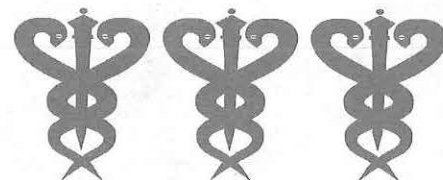
Four of the patients have failed to conceive: two DES-exposed women have primary infertility, and the third DES daughter, who has conceived before with intrauterine insemination, has not yet conceived. The last of the four patients has only one tube and that has adhesions, so conception seems unlikely.

The authors conclude that "an improved uterine contour may result in an improved pregnancy outcome." They note however that for the DES daughters with primary infertility, "an improved uterine contour may not result in enhanced fertility. The age of

these patients (36 and 38 years) at the time of surgery may also be a factor."

While noting that the number of patients with this surgery is too small to draw general conclusions, the surgeons do think that they have shown "that lateral metroplasty is both feasible and safe. Ideally, a study, probably at multiple centers, should be established to assess its efficacy. At present, we believe it will be of value in patients with recurrent pregnancy wastage but doubt it will improve fertility in patients having difficulty conceiving."

**Fertility and Sterility*, March 1993.



Join DES Action!



Yes - I want to get the answers about DES. Enclosed is my membership.

- ☐ Benefactor: \$1000 and above ☐ Supporter: \$100
☐ Sustainer: \$500 ☐ Friend: \$75
☐ Associate: \$200 ☐ Subscriber: \$60-\$30 (sliding scale)

All members receive **The DES Action Voice** quarterly. Those at the \$75 level and above receive additional annual reports on DES Action's work and progress.

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I am a: ☐ DES Daughter ☐ DES Son ☐ DES Mother of a ☐ Daughter ☐ Son ☐ Other

name _____

address _____

city _____

state _____

zip _____

phone () _____

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☸☸☸ dear doctor

Q: What is the treatment for testicular cancer?

A Removal of the affected testicle is necessary for diagnostic and therapeutic purposes. The type of tumor cell is then identified, and the stage of the tumor is determined by using CAT scans and tumor markers, which are obtained from blood samples.

Treatment may include observation, with periodic CAT scans and blood tests being performed. Radiation, chemotherapy or removal of internal lymph nodes are other

options of treatment.

The success rate for localized disease is 95%.

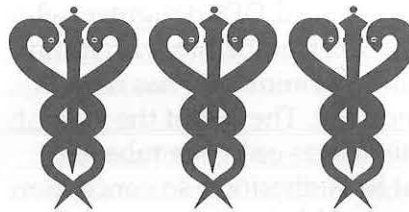
Henry J. Abrams M.D.

Asst. Clinical Professor of

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Albert Einstein College of Medicine

New Hyde Park, N.Y.



Is Your Doctor a 10?

We want to update our national directory of DES knowledgeable physicians. We'd appreciate getting names, addresses and phone numbers of doctors you've found competent: ob/gyns for mothers & daughters, urologists for sons. If an ob/gyn is experienced with high risk pregnancy and/or infertility care, we'd like to know that too. We especially need referrals for: **Alabama, Arkansas, Delaware, Idaho, Indiana, Kansas, Kentucky, Mississippi, New Hampshire, New Mexico, North Dakota, Oklahoma, Rhode Island, South Carolina, South Dakota, Tennessee, Utah, Vermont, West Virginia, and Wyoming.**

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