

## Editorial

THIS is our 20th anniversary year. Among other things, we are celebrating the occasion with a new look for the Voice. We hope you like it.

Some of you have been with us from the beginning, others are new to DES Action and the DES story. We hope that both groups will appreciate a little bit of DES history.

In May 1978 women from several local DES groups met in Washington to attend a DES Task Force meeting at the National Cancer Institute. It was our work that led to the creation of the DES Task Force, the first time that the NCI convened a discussion on DES with researchers and physicians. Would this have happened without us? Probably not.

After the Task Force meeting, we decided to form a national organization that could speak for all of us. We brought out the first issue of the DES Action VOICE in January 1979, with articles on the Task Force, the FDA, DES sons, DES legislation, and the colposcope. We had seven local affiliates.

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## DES Symposium a Big Success!

OVER 100 DES-exposed individuals and their friends and family members gathered October 18 in Andover, MA for a very successful DES Symposium. Titled "Pills and Potions: Reproductive Technologies, Menopause, and Our Future," the daylong event included four keynote presentations and five participatory workshops. Although the Symposium concentrated on reproductive technologies and the issues facing women approaching or in menopause, many other concerns arose throughout the day.

Some of those concerns included DES-related health effects on the immune system, and potential effects on the children of DES daughters and sons. We also wish we could have had more time for discussion of legal issues related to DES. We hope to cover more of these issues during the next Symposium.

Many expressed the desire for a two-day meeting, and we will

consider this as we plan the next gathering—tentatively scheduled for Fall 1999 in either New York or the Boston area. If there is sufficient interest from members in the Western region of the country we will also consider holding a Symposium somewhere in the West.

Evaluations for the day were extremely positive, with the most commonly cited benefit being the opportunity to meet other DES-exposed people. As one person put it, the experience was "both comforting and powerful."

The official transcript (for the morning presentations only) of the Symposium is now being prepared. We will announce its publication as soon as it is available for purchase.

Following the Symposium DES Action's Board of Directors held their Fall meeting. It was a productive meeting and elections for Board members and officers

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Questions from the audience at our October 1997 symposium.

## DES Action Affiliates

Each group was created and nurtured by volunteers. Write them if you want information on their activities or can volunteer.

### DES Action

#### USA National Office

1615 Broadway, Suite 510  
Oakland, CA 94612

#### Arizona

4855 East Warner Road, #24  
Box 180  
Phoenix AZ 85044

#### California

c/o Dr. Wingard  
Community Medicine M-007  
Univ. of Calif-S.D.  
La Jolla, CA 92093  
Box 661653  
Los Angeles, CA 90066

652 Cayuga Drive  
San Jose, CA 95123

#### Colorado

P.O. Box 2645  
Colorado Springs, CO 80901

#### Connecticut

Box 131  
Guilford, CT 06437

#### Louisiana

P.O. Box 804  
Chalmette, LA 70044

#### Massachusetts

P.O. Box 126  
Stoughton, MA 02072

#### Michigan

P.O. Box 2692  
Ann Arbor, MI 48106  
2205 Rosewood SE  
Grand Rapids, MI 49506

#### Minnesota

Box 3102 Butler Quarter Station  
Minneapolis, MN 55403

#### Missouri

7647 Carswold  
Clayton, MO 63105

#### Montana

491 Eckelberry Drive  
Columbia Falls, MT 59912

#### New Jersey

Box 762  
Fort Lee, NJ 07024

#### New Mexico

8401 Spain Road NE  
Apt. 2-G  
Albuquerque, NM 87111

#### Ohio

27060 Cedar Road, #507  
Beachwood, OH 44122

#### Oregon

1050 NE Butler Market Road, #3  
Bend, OR 97701

#### Pennsylvania

Box 398  
Nescopeck, PA 18635

#### Rhode Island

33 Edward Avenue  
Rumford, RI 02916

#### Texas

8230 Shadowwood Drive  
Waco, TX 76712

### Washington, D.C. Area

12494 Alexander Cornell Drive  
Fairfax, VA 22033

#### Washington

719-15th Ave. East  
Seattle, WA 98112

### DES Sons Network

Michael Freilick  
104 Sleepy Hollow Place  
Cherry Hill, NJ 08003

### DES

#### Third Generation Network

10731 Brookley Road  
Glen Allen, VA 23060

### DES Action

#### Canada National Office

5890 Monkland, Suite 203  
Montreal, Quebec H4A 1G2

### DES Action

#### Australia

P.O. Box 282  
Camberwell, Victoria 3124

14 Edmundson Close  
Thornleigh 2120 NSW

### DES Action

#### Belgium

DES Informatiecentrum  
Kolkensvijverstraat 18  
3201 Langdorp, Belgium

### DES Action

#### Britain

c/o Women's Health  
52 Featherstone Street  
London EC1 Y 8RT

### DES Action

#### France

Info DES/France  
9 Allee de Guignegault  
45800 St. Jean de Braye  
Reseau—DES France

44 Rue Popincourt  
75011 Paris

### DES Action

#### Ireland

Lower Ground Floor 16  
20 Cumberland St. 5

### DES Action

#### Italy

Centro Simonetta Tosi  
Casa Intern Donna  
Via della Lungara 19  
00165 Roma

### DES Action

#### Netherlands

DES-Aktiegroep  
Wilhelminapark 25  
3581 NE Utrecht

### DES Action

#### New Zealand

Prof. Charlotte Paul  
Preventive and Social Medicine  
Otago Medical School  
Box 913  
Dunedin, New Zealand

DES (diethylstilbestrol) is a synthetic form of the female hormone estrogen.

From 1938 to 1971, several million pregnant women in the U.S. were prescribed DES, especially if they had a history of previous miscarriage or slight

bleeding or had diabetes. DES was given in pills, injections and suppositories and sold by over 200 drug companies under their own brand names.

DES exposure can lead to health problems:

- DES mothers have a slightly increased risk for breast cancer.
- DES daughters have a 1 in 1,000 risk for a rare vaginal/cervical cancer, clear-cell adenocarcinoma. This is the reason all daughters need regular gyn exams. They also are at risk for reproductive difficulties: infertility, ectopic pregnancy, miscarriage and premature delivery, and should always receive high-risk pregnancy care.
- DES sons have an increased risk for undescended testicles, cysts on the epididymus, and possibly for infertility.

DES Action, the major consumer group working on this issue since 1974, has special publications, physician referral lists, attorney referral lists, this quarterly newsletter, and a hot-line: 1-800-DES-9288.



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**DES Action USA**  
1615 Broadway, # 510  
Oakland, CA 94612  
(510) 465-4011  
FAX: (510) 465-4815  
Hotline: 1-800-DES-9288  
e-mail: [desact@well.com](mailto:desact@well.com)  
<http://www.desaction.org>

#### Executive Director:

Nora Cody

#### Board Officers

President: Pat Cody  
VicePresident: Michael Freilick  
Secretary: Karen Renick  
Treasurer: Stephanie Kanarek

#### Contributors:

Nora Cody  
Pat Cody  
Karen Renick

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# The Health Legacy for DES Daughters

*Board Member Karen Renick spoke at a recent conference organized by Vivian Pinn, M.D., Director, Office of Research on Women's Health. Here are excerpts from her speech.*

UNLIKE many of you, I am not a clinician, an academic, or a research scientist. I am here because I have been profoundly affected by a pharmaceutical "magic bullet" that went terribly awry. And hence, because of this life-altering experience, I stand before you today as a women's health advocate.

In writing this testimony, I realized that nearly ten years have gone by since I first learned that I had been exposed to DES in utero. And yet, I can still recall most vividly the feelings of disbelief, fear, sadness and isolation that overcame me following my first enlightening conversation with the specialist to whom I had been referred. I was 35 years old at the time and I had never heard of the drug DES. For nearly twenty years prior to this experience, I had been going regularly to reputable gynecologists and not one of them had detected the telltale signs of my DES exposure, much less even discussed the possibility of my exposure to the drug. It was the wonderful midwife to whom I had turned for my health care, in excited anticipation of becoming pregnant, who detected my probable exposure on my first visit to her office. Mine is not the story of someone living in a small rural town. I was living in New York City.

What I would gradually piece together over time was the

forgotten happenstance that my mother had been prescribed the drug diethylstilbestrol (DES) while pregnant with me in 1951 because she had suffered a miscarriage in her previous pregnancy. Her doctor was simply doing what most of his peers were doing at the time and would continue to do for twenty more years. He prescribed an FDA-approved drug that was persuasively and aggressively advertised by the pharmaceutical industry for use with pregnant women to not only, as advertisements claimed, "prevent abortion, miscarriage and premature labor", but to also help them have "bigger and stronger babies."

My mother, like pregnant women everywhere, wanted nothing more than to bring a healthy baby into the world. She trusted the assurances that the drug was safe and effective. DES was neither. My mother had no way of knowing that the drug she was taking was actually harming the same child she sought to protect.

Sadly, she had no way of knowing what researchers had already discovered in 1941 with laboratory animals: that DES, when given to pregnant rats, caused reproductive tract abnormalities in both the female and male offspring. She also had no way of knowing that by that same year there were over 40 published articles in U.S. and European medical journals documenting carcinogenic effects in animals from natural estrogens and synthetic estrogens, including DES.

But the pharmaceutical industry, applying to the FDA for approval of DES, did know, and chose to exclude the animal studies while only emphasizing positive anecdotal clinical reports in its application to the agency. As the legal scholar and author Lucinda Finley wrote in her treatise of 1996, *The Pharmaceutical Industry and Women's Health*:

*The exclusive focus of the pharmaceutical industry on what DES might do for women, instead of also considering what it might do to women, demonstrates greater concern for controlling the female reproductive system for profit than for the ultimate health and safety of women.*

Because of my exposure to DES, my reproductive system is so severely deformed that I am unable to bear a child of my own. Like the DES mothers before me who would give anything for a successful pregnancy, I underwent repeated rounds of fertility drugs desperately trying to prove the statistics were wrong. I do not know the effect these fertility drugs might have on me as a woman, much less the effect they may have on me as a DES daughter.

Because of my DES exposure, I nearly died from an undetected ectopic pregnancy. Silently, I face the fear of cancer. I am now entering my menopausal years which also causes me great concern because of my prenatal "bath" in high levels of estrogen. No one can alleviate these fears

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# Internet Resources

## Online Support

TASC, The American Surrogacy Center, hosts DES-L, an online support group for DES daughters. The purpose of this listserv is to provide support and exchange information with other DES daughters (currently over 200 members) via the internet. Besides communicating through e-mail,

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DES-L offers an online bulletin board, live chat sessions, and virtual seminars (at which professionals such as

physicians, attorneys, psychologists, and researchers are available to discuss your questions and concerns).

DES-L's webpage at [http://www.surrogacy.com/online\\_support/des/](http://www.surrogacy.com/online_support/des/) has DES articles, links to other DES websites, and an application to join the listserv. Hope to "see" you there.

## DES newsgroup

There is also a DES newsgroup—check to see if your server carries it. It is called **alt.support.des** and it is a newsgroup for DES exposed daughters, sons, and moms. The purpose of this group is to exchange information, provide support, and post DES related announcements.

## DES Action website and e-mail

And don't forget that DES Action has a website at <http://www.desaction.org>, and our e-mail address is [desact@mail.well.com](mailto:desact@mail.well.com).

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of mine because there is no research that I can turn to for the answers to my questions.

I am but one of a vast, highly dispersed and diverse population of ten million Americans all closely connected by the common bond of having been exposed to the most destructive estrogen ever created, DES. We illustrate one of the first examples of grand-scale toxic exposure, the effects of which do not surface until decades later....

Research on the long term effects resulting from DES exposure is far from conclusive, and must be pursued to do justice both to our population and to all women. DES animal studies completed to date, as well as preliminary clinical studies, indicate that the effects of DES may be much broader than first thought. For this reason, the endocrine, skeletal, cardiovascular, neurological and autoimmune systems all need to be examined thoroughly.

Although DES is better known because of its link to cancer, the effects of exposure go far beyond cancer to include both obvious and subtle changes to reproductive function. Because of this, DES is also a critical example of a hormone disruptor. We would do well to learn as much as possible from the DES experience as we seek to understand the full implications of long-term, worldwide exposure to endocrine disrupting chemicals. It is not surprising that most of the leading scientists who are calling for an investigation of estrogenic chemicals pervasive in our environment are carefully studying the known effects of DES.

As with today's widening understanding of the power of

estrogen to affect our bodies, we need to follow through and learn as much as possible about the DES model. The time of this research is especially critical now as DES daughters approach the age of menopause because researchers suspect even greater risks for DES-related problems occurring as a result of this major hormonal shift.

Among the questions DES Action repeatedly poses to researchers are the following:

- Will there be a new peak of clear-cell vaginal or cervical cancers as DES daughters reach menopause? Will DES cancer daughters suffer recurrences triggered by a new hormonal milestone?
- Will DES daughters, as we age, develop an increased rate of breast cancer as animal studies seem to suggest?
- Should DES daughters be candidates for hormone replacement treatment during menopause?
- What are the long-term effects of fertility drugs on a population already exposed to synthetic estrogen in utero?
- What are the effects of DES on the endocrine, skeletal, cardiovascular, neurological and immune systems?
- Are there risks for the third generation, that is, the children of DES daughters and DES sons?

I look forward to working with colleagues in the health professions and in the DES community to developing a women's health research agenda that will truly serve not only the women in our population of the DES exposed, but all women, today and in the future.

DES FALL SYMPOSIUM from page 1...

were held. Board members Candy Tedeschi, Stephanie Kanarek, and Libby Saks were elected to second terms. Former Board member Kari Christianson was elected to a new term, as was Sally Keely, one of the leaders of DES activities online via her website and the DES daughters online mailing list (see "Internet Resources" in this issue). The Board warmly thanked and bid farewell to departing members Amanda Sherman and Karen Lang. The officers of the organization are now: Pat Cody, President; Michael Freilick, Vice President; Karen Renick, Secretary; and Stephanie Kanarek, Treasurer.

At our Symposium workshops, we had a session on osteoporosis presented by Joseph M. Carlin, R.D., regional nutritionist with the U.S. Administration on Aging. Among the material he distributed was this information from the National Osteoporosis Foundation:

"While ERT can be beneficial, it also has risks and should be undertaken only after a careful discussion with your doctor.... For postmenopausal women who cannot take ERT, calcitonin may be an option. Calcitonin is a hormone produced in the thyroid gland that is involved in calcium regulation and bone metabolism.

This hormone has been shown to slow bone loss. A preparation of salmon calcitonin is approved by the U.S. Food and Drug Administration (FDA) for the treatment of osteoporosis.

Calcitonin has few side effects and is safe. It is administered by injection, however, studies are underway to approve its use as a nasal spray....

#### Calcium: A Necessity at Any Age

Children aren't the only ones who need calcium. Because bone tissue is constantly building up and breaking down, calcium is important for those of all ages. To prevent osteoporosis, you need to eat a balanced diet rich in calcium throughout your lifetime.

- Postmenopausal women on ERT need 1,000 mg of calcium daily.
- Postmenopausal women not on ERT need 1,500 mg of calcium daily.

Adding more calcium to your daily diet is easy. Add a dairy product to every meal by grating cheese over your salad, or adding low-fat cheese to your sandwich. Try low-fat yogurt or frozen yogurt for dessert. Enjoy other high calcium foods like broccoli, canned salmon with bones, and calcium-fortified fruit juices.

Some people have difficulty digesting milk products, a condition known as lactose

intolerance. People who are lactose intolerant can satisfy daily calcium requirements by incorporating non-dairy, calcium-rich foods into the diet, taking calcium supplements, and by using lactase pills or drops which make the milk products digestible.

#### Exercise for Strong Bones

Regular weight-bearing exercise, which causes muscles to work against gravity, helps to build and maintain bone mass. Walking is an excellent weight-bearing exercise, as are jogging, tennis, aerobics, and dancing. Experts believe that other forms of exercise, like swimming and bicycling, while not weight-bearing, have cardiovascular benefits as do many weight-bearing exercises....

Certain substances are toxic to bones, such as nicotine and alcohol.

#### Bone Density Testing

Once bone mass has been lost, it can't be replaced. That's why the best 'treatment' for osteoporosis is preventing it in the first place. Since osteoporosis can develop silently for decades until a fracture occurs, early detection of low bone mass is essential so that therapy to prevent further bone loss will be most effective. Safe, accurate and non-invasive tests are available for measuring bone mass.

EDITORIAL from page 6...

Since that time we have never missed an issue of this newsletter. You are now reading issue 75 which goes to thousands of individuals as well as 25 affiliates in the U.S. and 9 in foreign countries.

Your support has been decisive

in all our accomplishments, especially our legislation that provides money for research and for public and physician education. Would this have happened without us? Assuredly not.

Our National DES Advocacy Project has started, working to

bring DES information to individuals and to physicians all over the nation. We'll keep you posted, and we look forward to continued collaboration with all our friends and colleagues in the DES community.

# DES used on "too tall" girls in Australia

Drug prescribed in appalling medical experiment

**EARLIER** this year Australian newspapers reported an inquiry into the use of DES to stunt the growth of young girls considered "too tall." Pediatricians gave DES to 168 girls in Victoria, Australia, from 1959 until 1975—four years after the link between DES and clear cell cancer was established. The DES was given to them daily to "make their skeletons age faster and stop them growing."

Researchers stated that DES was given because of concern over the problems the girls might face "finding boyfriends, buying clothes or becoming ballerinas." An excerpt from the research papers justifying this treatment and published in the paper *The Age* noted the following:

"Some girls feel so embarrassed with boys shorter than themselves that they believe their choice of male companions, both in the immediate future and as adults, will be seriously jeopardized."

"They may have difficulty in buying clothes appropriate to their age, and if clothes have to be tailor-made, extra expenses can be a problem."

"Some careers, for example classical ballet, are closed to an unusually tall girl."

How tall is "too tall?" One 13 year old girl with an estimated adult height of 5 feet, 8 inches was given DES because "good evidence was produced that her prospects as a ballerina were outstanding but her estimated mature stature would have made this career impossible."

Researchers, who gave the drug to girls aged 10 and older, concluded that DES was "effec-

tive in controlling the stature of potentially tall girls." They also found out that it brought on puberty more quickly and disturbed normal menstruation. Then, in order to induce regular menstruation, some girls were given monthly doses of another hormone, norethistrone. Other side effects of the hormone study, which was partially funded by Australia's National Health and Medical Research Council, included weight gain and darkening of skin pigmentation. The researchers' conclusion? That DES is "effective in controlling the stature of potentially tall girls, but great care is required in the assessment and management."

Janet Cregan-Wood is a leader of today's movement to fully investigate the effects of DES on the "tall girls." In a follow-up letter responding to this article, she writes:

"We are the 'tall girls' who were treated with stilboestrol in the 1960s and 70s. Contrary to G. Barnes's assertion (*The Age*, 9/7), we were not 'public-spirited individuals who volunteered for treatment.' Neither we, nor our parents, ever knew that we were part of an ongoing experiment."

"Explanations may have been given at the time about the pros and cons of the treatment, but we had no knowledge that there were also serious concerns, voiced by other researchers at the time (Bayley et al in *British Medical Journal*, April 1963), with regard to the efficacy and desirability of such treatment."

"We have experienced, and are still experiencing, a multiplicity of health problems (including

infertility, ovarian cysts and immune problems).

"Stilboestrol is the one common factor and it has been implicated for a long time in such health problems. No one has ever followed us up to determine definitely what the long-term effects of this medically unnecessary experimentation has been upon us. We require a properly conducted epidemiological follow up, not paternalistic reassurance that the treatment given to us was without fault, ethically and medically."

In a speech which was read at DES Action's Fall Symposium, Ms. Cregan-Wood echoes a common sentiment voiced by people exposed to DES in utero.

"We have some cause for concern. No one has been able to categorically allay our anxieties. All that the medical establishment has been able to say is that they don't know, but then they've never looked. And that's what we want them to do."

She goes on to describe the DES treatment.

"What basically were these trials all about? Girls, who were considered to be growing too tall, were measured and X-rayed, and estimates were made of their mature height. Stilboestrol, DES, was prescribed daily. This had the effect of speeding up the maturation of skeletal growth."

Treatment for some was as little as six months, whilst for others, it lasted up to four years.

"...What they did was medically and morally unacceptable, not just with hindsight, but even back then."

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## Book Reviews

JANINE O'LEARY COBB, *Understanding Menopause: Answers and Advice for Women in the Prime of Life*, Plume Books, published by Penguin Books, 375 Hudson St., New York NY 10014. 317 pp. Paperback, \$12.95.

Those of us who heard Janine O'Leary Cobb at our October Symposium know how straight forward and knowledgeable she is—a friend indeed, like the title of her newsletter. In the introduction to this book she writes,

"When I started, I had no idea that it would take so long to achieve any level of credibility, or even that menopause was seen as the sole domain of the medical doctor. Perhaps I'm naive but I wonder why female adolescence—which represents a transitional stage between non-reproductive and reproductive status—can be discussed by psychologists, social workers, physicians, and adolescents themselves, whereas menopause—a transition between reproductive and nonreproductive status—has somehow become the bailiwick of the gynecologist? When any sort of informational meeting or presentation is planned about menopause in the United States, the organizers immediately think of inviting a gynecologist. Rarely is a menopausal woman part of the program...."

(DES Action has had parallel experiences—only someone with an M.D. was supposed to talk about DES exposure. And it did take a long time for us to achieve credibility. In the early days when we managed to get interviewed on TV, a doctor was also included, and we had to brief him in the green room because most doctors were ignorant about DES).

Early on, Ms Cobb asks, "How much of a woman's experience is menopause and how much is aging?" She clarifies that, and a lot more, in the following sections of her book. They cover: physical ailments at menopause; strategies and remedies, medical and non-medical; psychological and sexual effects; hormones; increased health risks: osteoporosis, heart disease, cancer; surgical menopause; preparing for menopause—nutrition and exercise; relationships at mid-life; aging and appearance, and, in conclusion, resources.

ANN M. VODA, *Menopause, Me and You: The Sound of Women Pausing*. Harrington Park Press, Haworth Press, 10 Alice St., Binghamton NY 13904. Paperback, 396 pp. \$24.95. (For DES Action members, \$19.96 if ordered with reference NBA 97).

Dr. Voda, who is Professor of Adult Physiological Nursing at the University of Utah, is a

specialist on the health of middle-aged women. In the preface to this book, she writes that she has "included the voices of many women, in various stages of menopause, who describe what they are feeling as well as what it means to be a midlife woman at the closure of reproductive life. This is not a book...devoted to clinical treatment, i.e., 'how-to-treat' menopausal women. Instead, it is a book that describes the experiences of women who, with much ambivalence and some anxiety, both celebrate the end of menstruation and curse the changes they experience. ...I have included several self-monitoring tools that I have found useful for observing and naming the changes that occur during the transition to menopause."

Written in a personal way, *Menopause, Me and You* is divided into 23 chapters in four main sections: Preparing for the Journey; The Menstrual Cycle; Menopause, the Closure of Menstrual Life; and Keeping Records and Keeping in Touch. She has much to say on hormones, including this advice: "Abandon the terms 'estrogen replacement therapy' or 'hormone replacement therapy.' The terms imply that something is missing, causing a disease, and needs to be replaced...Remember, estrogen is not a miracle drug and menopause is not a disease."

"TALL" GIRLS from page 6...

"They did not take due caution. They did not take note of research knowledge that was readily available. They did not inform people they were treating, that they really did not know exactly what outcomes could

be expected."

"...why does (the medical establishment) so readily medicalise female states of being and seek to alter them?"

We have heard reports that DES was used for this purpose in

other countries as well, including Great Britain, the Netherlands, and the U.S.

We join DES-Tall Girls in calling for long-term follow-up to determine the effects of this unethical use of DES.

# Letters to the Editor

DEAR Editor:

Thank you for fighting the good fight re DES. I heard a program several months ago mentioning thyroid problems secondary to DES—first time I'd heard of that possible connection—and then I remembered.

In 1951 when I was 27 and three months pregnant I began to show signs of losing the baby. The doctor gave me DES and I stayed in bed a while. No further problems with pregnancy—healthy baby.

Eleven months later I developed what turned out to be ferocious hyperthyroidism—treated unsuccessfully with

medicine, then finally in 1955 with radio-active iodine.

That first baby grew up healthy but at age 27 developed a significant thyroid problem, and of course now I wonder whether it might be DES-related. She did have a healthy baby and there are no apparent problems there.

Anecdotal data can become significant so I hope other women with similar experience may come forward. The possible connection between DES and thyroid would never have occurred to me if I hadn't heard that program. Perhaps further dissemination of the information will elicit more data.

*Reader in California*

DEAR Editor:

I am a DES daughter with reproductive complications. I

have had miscarriages, an ectopic pregnancy, T-shaped uterus, etc. But this letter is not about me. I have been blessed with a six year old healthy wonderful son and I have an eight month old beautiful daughter who has torticollis. Apparently torticollis has several causes, one of which is a restrictive intrauterine environment (a la T-shaped uterus). I am wondering if any other DES daughters have children with torticollis and how the treatment went. It is a neck problem with her head always tilting one way. My daughter has begun physical therapy which appears to be helping some. I am nervous.

My e-mail address is somara@unitedmedia.com and my phone number is (212) 293-8540.

T W E N T I E T H

DES

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A N N I V E R S A R Y

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## National Office

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Oakland, CA 94612

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