V O I C E

A FOCUS ON DIETHYLSTILBESTROL

Fall 1987

#34

Medical Reports on Fertility

by Judy Turiel, Research Liaison

ith DES daughters at increased risk for various reproductive problems, a range of medical reports concerning fertility are of interest, although they may not focus specifically on DES exposure. We briefly summarize three such articles here.

Infertility Diagnosis

A recent article (Fayez, J. et al, Am. J. of Ob. and Gyn., Mar. 1987.) compares two diagnostic procedures that doctors may recommend as part of infertility investigation: hysterosalpingogram (or HSG, an X-ray of uterus and fallopian tubes following injection of a dye to outline these organs), and hysteroscopy (directly viewing inside the uterus through a small incision, under local or general anesthesia). Of 400 women undergoing an infertility workup, 34 showed uterine

abnormalities associated with prenatal DES exposure.

When performed and interpreted by an experienced reproductive endocrinologist and radiologist, HSG was as accurate as hysteroscopy in diagnosing many uterine abnormalities, including "DES-associated uteri." Although hysteroscopy can allow a direct view of some specific internal abnormalities, no treatment is recommended for structural uterine changes associated with DES exposure; therefore, the far more complicated and invasive hysteroscopy does not provide significant benefits over the simpler HSG. In addition, HSG provides information about whether fallopian tubes are open (patent) or blocked. If HSG fails to demonstrate any uterine abnormality, the decision to proceed with hysteroscopy is controversial. The authors of this

report conclude, "We believe that hysteroscopy should not be considered as a part of the routine infertility workup, but, after a complete infertility workup and when no apparent cause is found, laparoscopy (viewing the exterior of pelvic organs through an incision near the navel) combined with hysteroscopy is essential for the completion of the investigation." It is not clear whether this operative procedure will provide useful information for a DES daughter. Before proceeding, risks and benefits should be discussed with physicians experienced with hysteroscopy and DES-related care.

Ectopic Pregnancy

Since DES daughters have a higher risk of ectopic (tubal) pregnancy than non-exposed women, it is important to be continued on page 8

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The Voice Has a New Look

s you have probably noticed, we've changed the look of the Voice. We've tried to make the newsletter more attractive and inviting, as well as easier to read. Our thanks to our graphic artist, Kristin Prentice, for all of her help and ideas in this venture.

We also will be including more articles on how you can get involved in both the DES issue and DES Action USA. We hope that you, our readers, enjoy our new look and we welcome your ideas and suggestions about topics for future newsletters.

** litigation

Get Into Action

DES Action USA could not have originated and grown without the dedicated efforts of volunteers. Today, we proudly boast the activities of over forty DES Action groups across the country and around the world. The foundation of 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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Path Cleared for Law Suits in California

n a landmark decision, a California judge has set the ground rules for DES-related injury suits against the drug companies. In July, Superior Court Judge Daniel Hanlon established a formula for calculating each manufacturer's share of the market during the years DES was prescribed. This means that many of these cases can now

go to trial.

The 1980 Sindell decision by the California Supreme Court allowed suits even when the plaintiff could not name the specific drug company. However, such suits do have to list enough manufacturers to cover a "substantial share" of the market. In the seven years since that decision, lawyers on both sides of the issue have been trying to resolve questions on the size of the market. The drug companies have wanted to cite as many as 400 businesses, while plaintiffs' lawyers charged that this was a tactic to inflate the market with "phantoms" in order to minimize any one firm's liability. Judge Hanlon has set out a mathematical formula using sales records and national samples of prescriptions. He has ruled that this formula will apply to known companies, not to "phantoms." Since California's decisions often influence the views of other courts, this ruling may help DES plaintiffs in many states.

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Action At The Local Level—

New Jersey State Screening Program

By Joanne Mantz

eceiving adequate health care for our special needs is a concern of each of us who is DES exposed. In New Jersey, our state-sponsored program helps DES mothers, daughters and sons receive the medical treatment we need.

It took a lot of work to get our state screening program started in New Jersey and just as much to keep it going.

On September 23, 1981, then Acting-Governor Joseph Merlino signed legislation which began the New Jersey DES screening program. At that time \$50,000 was appropriated and two regional clinics, at Camden in southern New Jersey and Paramus in north Jersey were established. Only the year before, Governor Byrne had vetoed similar legislation.

Since its beginning, the program has been a partnership between the state and county governments and DES Action/New Jersey volunteers, who provide peer support at the monthly clinic dates. The pro-

gram provides free initial medical examinations for DES sons and daughters, a toll-free hotline (1-800-225-0863) for information and counseling, and a registry for updated literature.

Colposcopic examinations and pap tests are provided for daughters. Sons are seen by a urologist/urological oncologist and semen analysis is provided, if indicated. DES mothers are seen as well. Funds are also available for annual meetings, thus giving an opportunity to both share experiences and hear speakers with various types of expertise.

When funding by The Dept. of Health was cut at the end of 1984, The Camden Clinic closed. But two of NJ's state legislators, Assemblyperson Bennett Mazur and State Senator Paul Contillo introduced bills to provide additional funding. Through the diligent efforts of DES Action/New Jersey this additional money was approved.

Again in late 1986 we received

word that there was no money available to operate the program beyond January 1, 1987. Again, Senator Contillo came to our aid, along with Assemblyperson Schuber, introducing bill S2566 which provided \$20,000 for the program. However, the bill became stuck in an assembly committee. DES Action/New Jersey circulated petitions and asked everyone to make phone calls and write letters. (These really do make a difference!) Finally on July 9, 1987 Governor Kean signed the bill into law, providing our current funding.

Presently, the program holds a monthly clinic at Bergen Pines County Hospital in Paramus, which is held in conjunction with the Bergen County Department of Health Services. It is available to all New Jersey residents. In addition a new mammography screening program is provided for Bergen county women.

The health department staff, headed by Josephine Anderson, R.N., B.A. is excellent. Even a continued on page 5

Join the Action List

DES Action USA is developing a list of all members willing to contact their Congressperson regarding legislation related to DES. When letters or phone calls are needed our action list can be referred to and will help us get quick results on important bills. If you are interested in being included on our action list, please fill out the coupon to the right and mail it to our San Francisco office.

Y	ES! I WANT TO JOIN THE ACTION LIST.
-	NAME
	ADDRESS
-	ZIP
	PHONE
	Please clip out and mail to: DES Action USA
	2845 24th Street
	San Francisco, CA 94110

getting into the action...

Write an Article for Publication!

by Laura Minor

🧻 o, you want to do something for DES Action but don't really want to get involved . . . or you live too far away from a group to go to meetings but still want to help. How about writing an article? It doesn't have to be written for publication in a medical journal. A short article for church or temple newsletters, PTA bulletins, or local newspapers is fine. You don't have to be an expert, just follow the steps below and you'll see how easy it is to reach a lot of people with very little effort. Even a letter to the editor will be read by more people in one day than one person could contact in a month.

First, choose your subject matter. Do you want to write about the effects of DES in general, or in daughters or sons only or perhaps just your own experience with DES exposure?

Once you have a subject, contact the editor of the newspaper or bulletin you want to publish in. Is she or he interested? How long should it be? A church bulletin may only want a few paragraphs while the local newspaper may want several pages. When is your deadline? If it seems too soon for you, find out when the next one is and give yourself a little extra time.

You have chosen a subject and have a place to publish your article. Do you need to do any research? A personal story needs little research. You may want to interview your physician to double check your terminology. An article about DES exposure in

"Even a letter to the editor will be read by more people in one day than one person could contact in a month."

general requires more investigation for most people. Try your local library. Call or write your nearest local DES Action group or the SF national office.

Now that you are well into your research, it's time to start on an outline. How much depth do you want to go into? How much space do you have? Try to make a mental picture of how much material you have. Do you need all of it? You may want to use index cards for organization. I use the old-fashioned outline format. Use what is comfortable for you. The outline helps you to be more coherent in the final product. It helps you to make the choice of how to break your subject matter into sections. For a very short piece, a simple list will probably be sufficient.

Write a rough draft. Read it over. Check your facts. Have someone else read it over, preferably an objective person who has some knowledge of grammar, punctuation and spelling. Try to listen to criticism and then ascertain if it is good advice. Do not throw out an article just because your "editor" doesn't like a line or two.

Conclusions can be difficult. Try to sum up your article with one or two sentences that convey your message succinctly (e.g. "Although DES exposure can cause multiple problems, with proper medical care most of them can be managed effectively," or "Although it was difficult to tell my daughter about her DES exposure, I'm glad I did. She is now under the care of an excellent physician and I know that any problems that do occur will be detected early and treated right away.")

It is a good idea to mention the addresses of the local and national offices of DES Action as places to contact for further information. This lets you off the hook for technical questions. If called for, add a short bibliography. You don't need footnotes for this type of article.

A few hints to remember:

1. Don't get in over your head. Be comfortable with whatever you are writing.

2. Don't make statements that are only your opinion unless you so state.

3. Try not to frighten people. Your goal is to inform people. For instance say, "The incidence of vaginal cancer is low," not "DES causes vaginal cancer."

Once you've typed your article (double or triple-spaced) and sent it in, you'll feel a sense of accomplishment. After you see your piece printed, you'll feel even better. You'll have helped bring an important issue to many people's attention. If even one more DES-exposed person is helped, you can thank yourself.

Don't be afraid if you haven't written anything in years. Pick up a pencil and a little self-confidence and start writing! **Laura Minor has been active in both the DES Action LA and CT local affiliates. She has had articles printed in several health publications.

bool

by Nancy Adess, Board Member

The Medical Self-Care Book of Women's Health by Bobbie Hasselbring, Sadja Greenwood, M.D., M.P.H., and Michael Castleman. (Doubleday, 1987. 263 pages), \$12.95.

eaders of The DES Action Voice will recognize the name of Medical Self-Care as the magazine from which we frequently reprint interesting and useful articles. Now, three key staff from the magazine have teamed up to compile a valuable book on women's health care. Bobbie Hasselbring is the Medical Self-Care women's health editor, Sadja Greenwood (author of Menopause, Naturally) writes a women's health column for the magazine, and Michael Castleman is the magazine's editor.

Guided by the Medical Self-Care philosophy—"It's not enough for doctors to stop playing God; the rest of us must get off our knees"—The Medical Self-Care Book of Women's Health helps us up by providing the information we need to understand many of the basic health issues we will confront during our life.

The book covers an enormous range of topics, grouped under

the headings Reproductive Health, Fertility and Childbirth, Mind and Body Health, Common Health Concerns, and Staying Healthy. The subtitle might well have been, "Everything you ever wanted to know about your health but had no one who would take the time to tell you."

Not only do the authors take the time to tell you, they tell you more than you would probably learn in a traditional conversation between a health-care giver and patient. Besides incorporating background information on each topic, they also present

"... a valuable book on women's health care."

practical advice drawn from both traditional and alternative treatment techniques, often followed by suggestions for self-care.

As further resources, each chapter contains a list of suggested readings, and an appendix lists "The Best Women's Health Organizations" (including DES Action).

The book does not have a sep-

LOCALS from page 3...
normal pap test result is reported back to the patient. The program's medical director, Herbert F. Neuwalder, M.D., performs the screening exams. Breast self-examination education is also given along with an opportunity to speak with a DES Action/New Jersey volunteer for peer support.

The program plans to publicize its services as much as possible with the goal of reaching everyone in New Jersey who is DES exposed. Of course, the program's success depends on available funding—we're gearing up for our next letter-writing campaign!

Joanne Mantz is Co-ordinator of DES Action/New Jersey.

arate section on DES exposure, but refers to the effects DES can have on a woman's health in its discussion of such health problems as cancer and infertility.

The Medical Self-Care Book of Women's Health includes topics you might not expect covered in a health book, but once you see them here you'll wonder why they've been omitted from other such books. A section on cosmetics, for example, ("Avoid the Not-So-Pretty Hazards") exposes the health risks hidden in many cosmetics, lists toxic ingredients to avoid, and suggests alternative brands. "Achieving and Maintaining your Perfect Weight" reveals the psychology of overeating, suggests why diets don't work, and gives advice on how to get beyond them. "Recovering from Rape and Incest" presents a sensitive discussion of these traumas and how to help yourself heal. Other such "unusual" subjects include lesbian health, breast health, injuryfree aerobics, and menopause.

There are a number of instructive drawings. The two that depict how laparoscopy and hysterosalpingogram are done will be especially interesting to DES daughters who have undergone these procedures.

Most of the chapters are short; all are written plainly, in language for the reader who does not have a medical background. For those who are frustrated by the difficulty of getting straight, helpful answers to their medical questions, try this book. It may spell relief.

La letters to the editor

Dear Editor,

I've been wanting to write the enclosed letter for a long time. I guess you'd call it an open letter of hope and encouragement for those who feel their situation is hopeless. Your newsletter is the only link of communication for a lot of us who have never met another DES daughter personally.

Last week I celebrated my daughter Jean's third birthday. I can still look back with memories as fresh as yesterday and remember what a long hard road it was.

Jean was my sixth and final pregnancy. My other failed pregnancies included two premature births due to an incompetent cervix, one ruptured tubal pregnancy and two miscarriages. In between pregnancies I was having laser treatments for dysplasia of the cervix. I remember the feeling of hopelessness and desperation after each failed pregnancy. Every time I would say "never again" or "no more." But as time would pass, the pain would lessen and there would be that new mother in the grocery line with a beautiful bundle in her arms. I had a Shirodkar (cerclage) procedure done early in my pregnancy and spent six months in bed.

No words can express the love I have for my daughter. Every day I am thankful for her. For some of us DES daughters our dreams can become reality.

Good luck to you who are trying and remember: Find a doctor who is knowledgeable about DES. Don't be afraid to change until you find one. It is worth it. Ask questions and do your own research so you can be as knowledgeable about DES as you can.

Gloria Sanders Walnut Hill, FL

Dear Editor,

Please let me share my experiences with Clomid and its possible drawbacks for you as another DES daughter. Actually, it all started in February. We had consulted our doctor about some help in conceiving. After several tests, they concluded that the problems were that I wasn't ovulating and that I had a very underdeveloped and T-shaped uterus.

The doctor gave me Clomid to help me ovulate. Unknowingly, I had conceived in February. I had absolutely no signs, I even had a regular period. I took the drug at the end of March also. On day 12 of my next cycle, I started spot-

ASK YOUR MOTHER PES ACTION

ting. I called the doctor. His associate told me that I was probably just ovulating and not to worry. The next day I was still spotting but didn't call because the associate made me feel as if I was overreacting. The following day I woke up at 4 a.m. spotting and with bad cramps. I called the doctor again and spoke with another associate. He told me that my ovaries were probably overstimulated and to just lie very still. An hour and a half later I was very sick. My husband took me to the hospital and the doctor met us there. They put me on an IV, drew blood, and did a sonogram. That's when they told me that I was pregnant and that since I was, my hormone level was high to support the placenta. Taking the Clomid pushed the hormones even higher, and caused ovarian cysts. I was in the hospital for three

The doctor had hoped that the pregnancy would survive, but it didn't. I had a miscarriage on Easter Sunday. The physician has said that the good side is that at least I can now conceive, which was a major hurdle to overcome.

The doctor and I have talked about this extensively and we are going to take preventive measures; hopefully this will not happen again. Firstly on day 23 of

PMZ-Post Menopausal Zest

Menopause can affect each of us in a very different manner. We have all heard the many stories of the disadvantages of this phase in our lives. However, menopause can open new and positive doors for us as well (i.e. entering into a new and exciting phase of our lives, increased sexual freedom without fear of pregnancy, etc.). We encourage our readers to send us letters about their own personal circumstances with PMZ for publication in forthcoming newsletters.

my second cycle after the miscarriage, I will be receiving a progesterone blood level test to determine my level without the Clomid. Secondly, each month before I take the Clomid, I will take a quantitative blood hormone test for pregnancy. If the levels are suspiciously high, I will refrain from the Clomid. Physically, I am feeling pretty normal. The emotional part is sometimes a little shaky, but it's getting better all the time.

My advice to others who may be considering or are now taking Clomid: patient beware. Unfortunately, many doctors are behind schedule and have many patients waiting to see them. They feel as if they are following the standard procedure in giving you Clomid to solve your fertility problems, when they should be getting to the bottom of your fertility problem. Besides, your case should not be considered standard because you are a DES daughter. If you haven't already, have a progesterone count blood test as I have mentioned above. Don't let your doctor tell you that just because you don't have strong signs (i.e. breast tenderness, bloating) that your period is coming, you must not be ovulating, and to take Clomid.

Merrell Dow, who makes Clomid, has told me that they have no evidence of Clomid endangering a pregnancy, and who knows maybe this pregnancy was just the one out of ten that statistics say naturally ends in miscarriage in the first trimester. My doctor, of course, will not make any speculation, not wanting to expose himself to legal liability.

Another important point I want to make is: Don't feel guilty or surprised by your emotions. With your hormones going crazy all of a sudden, you're bound to have ups and downs. I thought I was handling this miscarriage well until about two weeks afterward. My emotions got the best of me and I felt overwhelmingly sad and then angry. No matter how far along you are, you still have lost what you had hoped and tried for—a child.

I just hope that I have been able to help someone else with my experience.

Sincerely, Deb Robison Bridgeport, CT

DES Action Receives Grant Funding

ES Action USA has recently been awarded two grants to help us in our important work. We wish to thank:

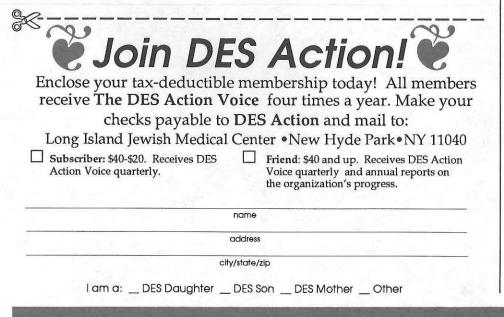
The Civil Justice Foundation for a \$3,000 grant to help support our National DES Action Media Campaign.

The L. J. Skaggs and Mary C. Skaggs Foundation for a \$500 grant which helped us to attend the fifth International Women's Health Conference in Costa Rica in May.

New Sons Brochure



ES Action has just had a revised brochure printed for DES Sons, thanks to a grant from the McKnight Foundation. This pamphlet includes information on how to find out if you are a DES son, effects of DES on sons, and what to do if you find out that you are a DESexposed son. Our brochure is being sent to urologists across the nation. We hope that it will be ordered for use in urology and family planning clinics. For more info about the brochure, or to order copies, please contact our San Francisco office.



REPORT UPDATE from page 1... aware of other factors that may increase this risk. One such factor is tubal surgery itself. A recent report provides information on the incidence of ectopic pregnancy following tubal reconstructive surgery (Lavy, G., et al, Fertility and Sterility, Apr. 1987). As this article points out, the chance of experiencing a subsequent tubal pregnancy varies depending on the type of surgery performed. The article describes several types of tubal surgery including procedures for removing a tubal pregnancy—and compares rates of tubal pregnancy following the various procedures.

In some cases, for example, when actual pregnancy has reached the emergency stage and must be removed immediately,

there is not time to discuss whether to have tubal surgery and if so, what type. However, you may be able to discuss the pros and cons of various options with your physician before surgery is required. For instance, DES daughters who wish to become pregnant may want to talk with their obstetrician about their risks of developing tubal pregnancy, how it can be detected, and preferred treatment should one occur. Remember, there is no way now recommended to prevent tubal pregnancy or to improve chances of conception.

Speaking of prevention, one report has identified vaginal douching as a potential risk factor for ectopic pregnancy (Chow, W., et al, *Am* . *J. of Ob. and Gyn.*, Dec. 1, 1985). This

study found that women who douched at least once a week had twice the risk of tubal pregnancy, compared to women who never douched. The highest risk was associated with commercial douches (over four times the risk, compared to women who never douched). This study did not examine the women's reasons for douching, although the increase in risk did not appear to be explained by existence of prior vaginal infections. The authors speculate that douching may contribute to subsequent pelvic infection, which in turn increases the risk of tubal pregnancy. Although one study is not definitive, you may decide that not douching is the cautious route to lower the chance of experiencing a tubal pregnancy.

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