V O I C E

A FOCUS ON DIETHYLSTILBESTROL

Fall 1991

#50

New Reproductive Technologies: Hearings in Canada

Simand, founder and President of DES Action/Canada, with Pierre Cadieux of Health and Welfare Canada. Harriet was one of 25 recipients, at the end of June, of the Canada Volunteer Award, given to honor those who have made outstanding voluntary contributions.

An important example of Harriet's contribution to health and well-being is the thoughtful testimony she presented last year at a hearing before the Royal Commission on Reproductive Technologies. Prefacing her statement with the comment that "The history and development of DES has a lot of parallels with IVF use and fertility drugs, and we don't want the DES tragedy to be repeated," she pointed out:

"With respect to in vitro fertilization...originally it was to be used for one purpose, which was, for women who have blocked

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Fallopian tubes. Now the indications are becoming more and more general. In fact, sometimes it may be used on women who are actually fertile but the problem is with the partner. You might also be aware of the Mc-Master study in which women on the waiting list for IVF seem to have a comparable pregnancy rate as women actually in the program.

In June 1990 the World Health Organization (WHO) came out with a report on IVF that stated that IVF and related technologies have not been adequately evaluated. Published results of randomized clinical trials to determine the true effectiveness of IVF are not yet available. Moreover, there has not been adequate research on the short term and long term risks associated with IVF and other medical treatments.

We also have concerns about the short and long term effects of a lot of the fertility drugs being prescribed to women in these programs. For example, Clomid is a very popular fertility drug. Animal research in the early 1980's indicated that Clomid is chemically very similar to DES and when Clomid and DES were given the pregnant mice, they produced the same effects in the offspring. Clomid is supposed to be prescribed before a woman



Pierre Cadieux and Harriet Simand.

becomes pregnant, but we have concerns about women who may accidentally be on Clomid when they do become pregnant and about the life span of Clomid, how long it stays in the woman's body.

We don't know about the longterm effects on women taking a lot of these drugs for super ovulation. Clomid is often used in combination with other drugs and there don't seem to be many studies on the combination effects of these drugs.

An article in the British Medical Journal by Fishel and Jackson entitled "Follicular Stimulation for High Tech Pregnancies: Are we playing it safe?" says the following:

continued on page 4

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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Another way to help us with our work is to give a Tribute Gift. You can honor a friend or relative on any important occasion by giving to DES Action in your honoree's name. We have Tribute Gift cards for this purpose that we can send to you.

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Notes From Nora

t was with the stories of women like Gina Carandas (see letters, p. 5) in my heart and mind that I recently traveled to Washington, D.C. to convey our message that "we need DES research!"

Margaret Lee Braun (Director, DES Cancer Network) and I attended a conference on women's health research sponsored by the Office of Research on Women's Health of the National Institutes of Health (NIH). Over 100 scientists and a small number of observers attended the conference, held in Hunt Valley, Maryland, September 4-6. The stated purpose of the gathering was to come up with recommendations for women's health research for the coming decades.

Our goal in attending was to see that the need for DES research will be included in the formal report listing the recommendations, and to meet and share views with research scientists from around the country. I am pleased to report that we accomplished both goals. One of the recommendations is for long-term studies following DES-exposed women to determine health outcomes.

After leaving Hunt Valley, we journeyed into the "campus" of the NIH, with 15,000 employees in a University-like setting in Bethesda, Maryland. We met with Dr. Sam Broder, Director of the National Cancer Institute (NCI), and directors or researchers from five of the NCI's divisions. We learned about the DES research the NCI funds and presented our concerns about other, presently neglected, areas needing research. I spoke about

the potential (as indicated by animal studies) for higher risk for genital tract and breast cancers in DES daughters, for breast cancer in DES mothers, and prostate and testicular cancers in DES sons. I also brought up our concern about the possible risks for DESexposed women who are exposed to additional estrogen in estrogen replacement therapy and tamoxifen, and requested that questions which screen for DES daughters and mothers be added to clinical trials currently studying effects of these drugs.

Margaret Lee Braun spoke about the late recurrences of cancer currently being seen in a small number of clear cell cancer survivors, and the fact that there has been no research on this unusual medical phenomenon or on the treatment outcomes or quality of life for all clear cell survivors.

In response to our concerns and as a way to draw together researchers and share knowledge towards new avenues for research, Broder proposed a special conference on DES which it is "highly probable" would be funded by the NCI, possibly in conjunction with other institutes of the NIH. A national conference could contribute a great deal to heightened awareness about the need for greater research into health effects. We will be following up closely with the NCI and other institutes of the NIH to ensure that such a conference does take place.

Washington, D.C. may be the ultimate "insiders" city, with more bureaucracies than one would ever care to learn about. As I made my way through the



Nora Cody, Executive Director of DES Action USA.

huge institutions of the houses of Congress and the National Institutes of Health, I constantly felt heartened by the knowledge that I was carrying a message from our community of millions of women and men exposed to DES. And I was pleasantly surprised to find wonderful, helpful people like Sandra Sobieraj in Congresswoman Louise Slaughter's office, who provided us with her sharp insight and offered her office as our "home base" on Capitol Hill; Cindy Pearson from the National Women's Health Network, who works every day as an advocate for women's health, and Dr. Bernadine Healy, the strong new director of the NIH.

All of your contributions to DES Action's Campaign for Research made this trip and our ongoing efforts possible. I thank each one of you and pledge that together, we will prevail and obtain significant research for DES-exposed people.

RESEARCH from page 1...

'...since current methods of potent follicular stimulation have been available and widely used only in the past three years, perhaps a cautious approach with individual stimulation regimens may be wiser than a blanket approach, particularly since reports of ovarian carcinoma developing during treatment have already been published.'

There doesn't seem to be much research into the causes and prevention of infertility just as when DES was on the market and nobody was researching why women have miscarriage or the causes for that. We do know that there are drugs or other devices such as DES and the Dalkon Shield and sexually transmitted diseases that do account for infertility. And these are all completely preventable.

Finally, I would like to look at long-term effects in terms of who is going to take responsibility if it turns out that there are long-term effects associated with any of these treatments or fertility drugs....

In 1971 when DES was linked to cancer, there was no publicity campaign by the government or the pharmaceutical industry to try to track any of these people down and provide us with the proper medical care. In fact, when I was diagnosed with cancer in 1981, I had never heard of the drug. I wrote to the government and asked what had been done and I was informed that since 1971 only one press release had been issued to the general public.

I also asked if doctors had been advising their patients if they had been given DES. I was told that there had been notices sent to doctors. However, we have been running DES Action since 1982 and in all that time have only heard of one woman who was actually informed by her doctor that she was given DES and that the children needed follow-up treatment. So women hear about this through the media but not through the sources that should be providing this information."

Among the recommendations DES Action Canada made to the Commission were:

'If IVF is to be used there should be controlled studies for each indication, first to show it is effective. We endorse the recommendations of the WHO:

'The effectiveness, short-term safety and cost of IVF must be scientifically determined through multi-centered randomized clinical trials. As a treatment for a given cause of infertility, IVF should be compared with other medical options or with no treatment.'

If we are going to continue on with IVF I think at this stage the most we can say is that it is an experimental treatment. DES Action recommends that medical records should be kept for at least two generations. At the moment, doctors and hospitals only have to keep records for five to ten years and from what we know about DES and long-term effects, this is just not sufficient.

We think that everybody should have full access to their own records. And if records are to be destroyed, they should be offered to the patient first.

In terms of long-term effects and responsibility, there should be special monitoring of children and women involved in all these programs and with these drugs. There should be a mechanism established now for contacting people if adverse effects show up. This probably should be joint between government and the pharmaceutical industry who might be producing these drugs. Doctors should be required to notify their patients if there are long-term effects, and perhaps a compensation scheme for druginduced or other iatrogenic injuries should be set up by the federal government, such as now exists in Sweden.

The last topic I want to turn to is informed consent.... I think it means not only that people should be fully aware of all the risks and benefits of a drug but also to be aware of what isn't known about a drug, what research has not been done, what possible effects might exist. And I would go even further and say that you can't really have truly informed consent unless there is enough research done so that you can make an informed decision.

We have special concerns for DES exposed women in any in vitro program. Most DES exposed don't even know they have been exposed. Any person in an IVF clinic should be asked if they were exposed to DES, because if they are, and they do become pregnant, they need special health care because they have higher risks associated once they do become pregnant.

Also, DES women have already been exposed to a very high dose of hormone and have been affected by it. We want to know if DES exposed women as opposed to non-exposed women have any added risks from taking more hormones. DES exposed

continued on page 5

🖾 letter to the editor

Dear Editor:

My doctor initially said my hysterosalpingogram showed my uterus to be "normal." The radiologist's written report said that I had an "abnormal, T-shaped uterus consistent with DES exposure." My doctor then reviewed the film and agreed. Other DES daughters report similar experiences. Why?

I am collecting anecdotal reports of doctors' apparent inhibitions about attributing physical deformities and infertility symptoms to DES exposure. I am concerned that many women aren't receiving information crucial to receiving proper medical attention.

Dr. Caren E. Glickson Stamford, CT

Dear Editor:

The purpose of this letter is two-fold. I want to share my DES experiences with others and strongly encourage all members

RESEARCH from page 4... women also run a higher risk of premature delivery, and one of the effects of taking fertility drugs is multiple pregnancy. We have concerns about the compounded risks of multiple pregnancy for DES daughters....

As a society we have a responsibility to ensure that tragedies such as DES never happen again. We have to ensure that 25 years from now we don't need to have an IVF or a Clomid action group."

"I now realize
that change is never easy
and when there is a
change to be made
we sometimes
have a price
to pay."

to become more active in the DES organization.

I cannot in mere words express my thanks and admiration to all of those already dedicated people of DES Action. They have accomplished great things for DES victims, while overcoming enormous obstacles. I have recently come to realize that it is through an overwhelming belief in the truth and a desire to help others that they continue to be determined and dedicated.

My story begins at age 13. When I began to menstruate my hair began to fall out in clumps. I am now 33 years old and I suffer from an auto immune disorder known as alopecia universalis. I have lost the hair over my entire body. Since 18 years of age my DES related surgeries include: cryosurgery, cauterization, biopsies, conization, exploratory laporotomy and a radical hysterectomy. I have also had a bilateral pelvic lymphadenectomy, a right oophorectomy and the removal of a right ovarian mass. Not to mention my partial vaginectomy. I thought it was over.

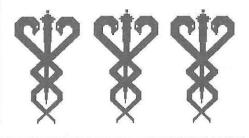
I have just recently experienced the pleasure of yet another hospitalization. I was hospitalized for major depression and an

eating disorder. I have of course filed suit against the drug manufacturers. Last week I faced them for the first of what will be many times. I can only say to you that it was the most inhumane experience of my entire life. I am beside myself with feelings of anger and disbelief.

I now realize that change is never easy and when there is a change to be made we sometimes have a price to pay. I thought of all those women who had gone before me. Women like Joyce Bichler and Andrea Goldstein and the price that they paid for you and for me. Last week was my worst lifetime experience but I want to fight because I believe in what I am doing.

I need the emotional support and encouragement of DES Action and its members. I need to know that others care, not just those who have been working all along. I need to know from those of you who may have been like me, putting DES Action on a second shelf. We need to change that. I resolve to make that change, to become more active. I ask that if that same need is present in you then you will begin to ponder that same resolution.

Gina Carandas Buffalo, NY



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¥¥¥ dear doctor

I am a 38-year-old DES daughter. My doctor has recommended a cervical cone biopsy performed by laser, along with an endocervical curettage, to diagnose and treat my symptoms of "Class II" Pap smears (which show "mild cellular atypia" and "squamous metaplasia") and a long history of intermenstrual spotting. He said that this would rule out any possible cancer below the surface. My doctor believes that the spotting is coming from the cervix which is chronically inflamed, and is undergoing squamous metaplasia.

I received a second opinion that an excisional cone biopsy is not necessary, based on my present symptoms, but that a D & C with hysteroscopy could be done to rule out other sources of the bleeding. Is this a generally accepted view? This doctor mentioned that the cone biopsy, even when performed by laser, can cause cervical deformity and severe cervical stenosis. What is the latest research on these and other risks or complications of laser cone biopsy, and are these risks more pronounced in DES daughters? What are the odds of cervical stenosis occurring in DES daughters, and what factors affect these odds? What impact does stenosis have on follow-up exams, i.e., is disease more difficult to diagnose? Also, what impact can it have on fertility? I heard the stenosis can cause cramping-is this only when you have your period? Does the tissue grow back normal (i.e., without adenoosis or cervical ectropion) after a cone biopsy?

Treating abnormal pap smears in DES-exposed women remains somewhat controversial. Clearly, there is a fairly high incidence of symptomatic cervical stenosis after cervical treatment for abnormal pap smears. This would include cryosurgery, laser ablation, and conization. The likely reason is that the cervical canal and the cervix itself are structurally different in DES-exposed women, with the endocervical canal being substantially smaller. Essentially, the treatment used in non-DESexposed patients without difficulty, yields significant problems with the anatomic deformities of the cervix associated with DES exposure.

As a general rule, cervical treatment should only be undertaken when there is a very clear indication to do so. The clinical diagnosis of dysplasia would fit that category. The term "mild cellular atypia" is not a clear-cut dysplastic process and can probably be followed with pap smears and save therapy for a change to a true dysplasia.

The comment regarding a

"possible cancer below the surface" seems somewhat unusual. The reason pap smears are effective is that the cells which are sampled reflect the changes in the cervical lining. It's certainly reasonable to do a colposcopy and perform a directed biop-sy or endocervical curettage. That's very different than an ac-tual treatment which has the potential for stenosis. If this patient had a colposcopy performed previously with benign findings on biopsy and endocervical curet-

tage, I would recommend simply

following the pap smears and repeating the colposcopy rather than anything further.

There are several possible causes for intermenstrual spotting. The first is that there's a superficial infection in the cervical lining (cervicitis). This is particularly common when there's a large transformation zone undergoing squamous metaplasia as is common in women with DES exposure. It happens in non-DES exposed women as well and typically the spotting is increased after sexual activity due to mechanical trauma.

Another possibility is that there's something within the uterine cavity such as a polyp or fibroid which is causing the bleeding. Typically the patient would have regular cyclic menses with superimposed irregular spotting. In that case a hysteroscopy and possibly D&C may well identify the source of the bleeding and remove it. A third possibility is simply that ovulation is not occurring regularly. Estrogenized anovulatory women frequently have irregular menses and their bleeding may well appear as intermenstrual bleeding. In that case the periods are typically erratic and vaginal spotting may occur.

Clear cell adenocarcinoma of the vagina may present with irregular bleeding. As a consequence, an exam is certainly appropriate whenever irregular bleeding is encountered and this possibility can be excluded rather promptly. It's very unlikely that a patient with previous exams would suddenly have this problem identified by the symptoms of intermenstrual bleeding.

Arthur F. Haney, M.D. Duke Univ. Medical Center Durham, NC

The Strengths and Limits of a Mammogram

by Deborah Wingard

ello! I am a 39 year old DES daughter. Last April 🗕 I had a routine mammogram which showed no abnormalities. In August during a selfexam, I found a nickel-sized (2 cm) lump in one breast. A repeat mammogram still showed no abnormality! I knew that mammograms could not pick up all tumors, but I always thought it was the small lumps one could not even feel that were missed. Not so. A mammogram cannot detect any lump the same density as breast tissue, and these lumps can be cancer (although they are usually not). In my case, the lump was mainly breast tissue, changing in response to a small (1 mm) intra-ductal carcinoma. Because of other changes in the biopsy, it was recommended that I have a modified radical mastectomy. This proved appropriate, as a second small primary site was found, as well as many precancerous changes. Given the early stage of the tumor at surgery, my prognosis is very good. What I would like all women

to know, but especially DES exposed mothers and daughters is that mammograms are not enough. They are vitally important—mammograms pick up many small cancers before they can be felt. However, self-exam is also vitally important, even the

My oncologist mentioned that breast cancer is on the increase in young women, and that we don't know why. (Sound familiar?) I would like to hear from all DES daughters who have had breast cancer, and particularly to hear what type of breast cancer they had. This may give researchers such as myself a clue about any possible association between breast cancer and prenatal exposure to DES. Hopefully there is no connection.

Good health to all of you!
Debbie Wingard, Ph.D.
Associate Professor of
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month following a clear mammogram! Both techniques together greatly increase the chance that if breast cancer occurs, it is caught at an early, treatable stage, when survival rates are high.

Second, I would like to encourage all DES daughters to have an early baseline mammogram and frequent physician exams, in addition to monthly self-exams. My gynecologist suggested I have my first mammogram around 35 years and that he examine my breasts at least once a year. (He sees me every six months). He felt this was especially important in young women because their cancers are frequently caught at a later stageprobably because they are not expected by either the women or their physicians. Also, he felt there is still too little information on the risks of DES daughters as they approach their 40s and menopause.

I know self-exams are not easy and are scary, but please do them. It may save your life. I am sure it saved mine.



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I am a: □ DES Daughter □ DES Son □ DES Mother □ Other

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DES Action USA

Highlights of 50 Issues

his is a Golden Anniversary for the Voiceour Issue No. 50! Since January 1979 we have been bringing our readers the latest research information on DES as well as answers to questions in our Dear Doctor column, personal stories, legal news, letters to the editor, and book reviews. For those readers who did not see some of the earlier issues, here are some feature articles that are the most frequently requested. You can order a copy of these articles for \$1 each, or, \$2.50 for the entire issue in which we printed them.

- Warning on Cryo-Surgery, Vol. 3 # 1, Summer 1981
- Psychological Impact of Infertility, Miscarriage, Stillbirth and Premature Delivery, Vol. 4 # 1, Summer 1982
- Progesterone Exposure in Pregnancy,Vol. 5 # 3, Winter 1983
- Deciding about Fertility Treatment, #21, Summer 1984
- Health Histories of the DES Exposed; Immune System Impairment, #27, Winter 1986

- The First Hurdle was Conception (report on ovulation pump), #30, Fall 1986
- Clomid: Too Much, Too Soon?, Issue 33, Summer 1987
- Estrogen Replacement: Two Views,
 Issue 35, Winter 1988
- Ten Years of DES Action, Issue 37, Summer 1988
- When is Enough Enough? Issue 39, Winter 1989
- Report on Research Conference, Issue 43, Winter 1990

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