A FOCUS ON DIETHYLSTILBESTROL

Summer 1993

#57

NCI Announces DES Grants

by Nora Cody

he hard work of so many of you, our Board of Directors and staff has resulted in two recent "Requests for Applications" (RFAs) for grant monies from the National Cancer Institute (NCI). These long-awaited grants will fund programs of vital concern to DES-exposed people.

In direct response to legislation which DES Action and the DES Cancer Network spearheaded, the NCI recently announced grants for the "National DES Educational Program for Health Professionals and the Public." Grants totalling \$5 million, and possibly more, will be awarded to up to five threeyear-long pilot projects. All grantees will work cooperatively, sharing information and some resources, and it is hoped that through this program health educators will learn the best methods for reaching and educating the public and health care providers.

INSIDE

Prodigy and Grateful Med

Long-term Risk of Fertility Drugs? "Based upon
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calls from DES mothers,
daughters, and sons, there
is enormous frustration
from these individuals
of not being able to
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doctors."

Excerpted from the RFA:

"The proposed DES educational projects should focus on the development, implementation, and evaluation of interventions aimed at DES exposed mothers, daughters and sons, and grandchildren. In addition, DES educational programs should be designed for health care professionals, including primary care physicians, oncologists, pediatricians, nurses, nurse practitioners, and other relevant allied health personnel."

"Awardees will be expected to participate actively in the development of a National DES Educational Program whose objectives are:

1. To document the barriers and test strategies to improve the

appropriate identification, diagnosis, and treatment of DES-associated medical conditions among primary care physicians, oncologists, urologists, other health professionals, and DES-exposed target populations in defined geographic areas.

2. To design, implement, and evaluate the DES Educational Program in several regions of the U.S., to increase health information about DES exposure and to improve the early detection, diagnosis, and treatment of several medical conditions associated with DES exposure for the relevant target populations.

3. To participate in a working group of medical experts and consumer representatives to present papers, for publication in a peer-reviewed journal, on standards for diagnosis and treatment of DES related medical conditions related to vaginal and cervical cancer, breast cancer, reproductive problems and issues, infertility, congenital malformations, and developmental abnormalities."

Applicants were encouraged to propose innovative models for reaching both unidentified and identified DES-exposed people and their health care providers. The RFA noted that "Based upon the thousands of calls from DES mothers, daughters, and sons, there is enormous frustration

continued on page 7

DES Action Affiliates

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

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DES Action/Netherlands DES-Aktiegroep Wilhelminapark 25 3581 NE Utrecht

Is Your Doctor a 10?

e 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 and daughters, urologists for sons. If an ob/gyn is experienced with high risk pregnanc 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 Wyoming

Please send this information to us at the national office, 1615 Broadway, Oakland CA 94612. Or, if it's easier, call us at any time at (510) 465-4011.

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

A DES Heart to Heart

by Gail Eichenthal

e tried something new at our June meeting of DES Action/Los Angeles, something so simple that I'm amazed at how profoundly it has affected me.

Normally we invite a doctor, nutritionist, attorney, or other knowledgeable sort to enlighten us on some aspect of DES exposure and its manifold consequences. Inevitably during the question and answer period, scraps of personal stories emerge, hastily told. After three or four such meetings, it finally dawned on those of us on the DES Action/LA steering committee that we might all benefit from the opportunity to talk informally about what DES has meant in our lives. Our invitations, then, were: A DES Heart to Heart—what has DES meant in your life?

We gathered on a warm Sunday afternoon in the beautiful flower-bedecked home of our cochair Marla Eby's mother. We viewed a videotape of a sobering report on DES that originally aired as part of the PBS series "Health Quarterly" last summer. Then our gathering of just under twenty—DES daughters, mothers and one son—broke up into two groups to give each person a chance to address the question, "How has DES affected your life?"

"Funny you should ask," replied the one son in our group, a successful writer. "I've just had my second testicle removed, having been diagnosed with primary testicular cancer for the second time in several years." For all of the physical ordeal of his surgeries and subsequent

"...Simply having the chance to share our fears and pain with others who truly understand was fantastically consoling. (Not to mention the joy in, for once, not having to explain what DES is!)."

chemotherapy, this DES son says his greatest challenge at the moment is depression.

Both of the DES moms in our small group expressed grave concerns for their children, who are beginning to think about starting their own families.

Both mothers (neither of whose kids attended the meeting) were forthright and well informed, and both won praise for their honesty and courage from the DESexposed son and daughters present, nearly all of whom have trouble communicating with their guilt-ridden parents about DES. Interestingly, neither of the mothers said much about her own health concerns. Conversely, several DES daughters expressed frustration that their mothers weren't taking the threat of breast cancer and other DES-related problems seriously.

This cross-generational aspect of our group was somehow very therapeutic. As our other founding co-chair, Sherry Weinman, remembers: "The son and daughters were able to offer assurances that they harbored no ill will toward the moms who'd taken DES. And the mothers were able to offer some of what mothers do best—comfort. For many of us, it was an opportunity to try out some of the things we wanted to say to our own mothers."

I wish I could report that the multi-generational power of DES injuries seemed diminished amidst such a supportive atmosphere. On the contrary, I came away with renewed fury and awe at the havoc it has wreaked. Among the DES-exposed offspring in our group, we've collectively endured vaginal cancer, the aforementioned testicular cancer, infertility, teenage menopause, numerous miscarriages and innumerable surgeries. Less well-documented results of DES experienced by the group include thyroid disease, pituitary tumors and depression.

The words of the Brooklyn DES specialist quoted in the PBS report keep reverberating in my mind: "DES is the worst example of human experimentation in the last century."

As Sherry Weinman says,
"One word we heard over and
over in our groups that afternoon was 'rage.' And how
interesting that it was spoken in
soft, almost quiet tones by
people who in many ways were
old hands in coping with the
medical repercussions of DES,
but still felt such intense feelings
about the emotional issues."

Perhaps due to vacations, graduations and weddings, this mid-June meeting was the least well-attended that we've had.

continued on page 4

VOICE

LA from page 3...

Yet for many of us, it was by far the most meaningful. The ramifications of DES can be such a lonely nightmare, not only for those who've survived cancer and other serious health problems, but even for those whose greatest affliction is fear. We simply don't know what DES has in store for us as we get older. No longer are we 'safe' from cancer once we pass the age of 26, as formerly believed. And the more we learn about DES, the more devastating its effects appear to be.

Yet simply having the chance to share our fears and pain with others who truly understand was fantastically consoling. (Not to mention the joy in, for once, not having to explain what DES is!).

And perhaps paradoxically, I think many of us came away with a renewed sense of hope. We intend to turn our rage into work: to more actively shape our futures, to ensure that another pharmaceutical holocaust never happens, to spread the word about DES to the untold millions of exposed people that aren't even aware of their condition, to help lobby for more comprehensive research. At the end of our meeting, the collective energy level of our group could have launched a missile.

But I have to admit that my most salient memory of that very emotional Sunday afternoon was the way the intense late afternoon southern California sun lit up the flowers in Marla's mom's backyard. I remember a feeling of such comfort and security, basking in the reflected sunlight, and in the warmth of my newly found friends. Here, at least, I felt safe.

Eletters to the editor

Dear Editor:

I am a DES daughter of 42 who has several of the more common, well-documented physical problems. I also was recently diagnosed as having congenital hip malformations severe enough to require total hip replacement. As there is no history of this in my family and as the NIH has documented that DES impacts on bone development (though they have not directly studied the impact of DES on hip formation), I would like to hear from anyone who is also experiencing similar problems. This may include hip or knee problems, problems in walking, or any kind of joint

Jenny L. Cox-Steiner 84 South Gillette Ave. Bayport, NY 11705 (516) 472-1268

Dear Editor:

As per the enclosed, I wanted to let you know of the new arrival at our house. Steven



Michael was born March 22, six weeks early, a healthy premature boy. The picture is Steven at

14 hours: 4 pounds, 15 ounces; he is now over 10 pounds. I know I was always interested in other daughters' successful births as reported in the **Voice** and I wanted to share my good news.

I am now 37 and it was two years of doctor visits, basal body temperature, ovulation tests, etc. before Steven was conceived. All

the tests, on my husband and me, in doctors' offices and hospital, including a hysterogram, said there was no reason that I was experiencing difficulty in conceiving. Then, June 12, 1992, I had what I had decided was the final test—a laparoscopy. A cyst was removed from what is now being referred to as my "better" tube. Within two months, to the shock of family, friends, and my gynecologist, Steven was conceived. So unlikely was it thought that I would be pregnant that my now ex G.P. recommended that I seek psychiatric care for the morning sickness I was experiencing.

The pregnancy was difficult, not catastrophic. The horrible morning sickness lasted three months. Pre-labor and bed rest started in month six, and a scary but thankfully successful short (three and a half hour) labor took place six weeks before term.

I'm not sure that Steven's arrival makes any universal statement for all DES daughters. What he does represent is the possibility for some to succeed in giving birth, with a lot of worthwhile physical and emotional pain. Of course, I have friends who have adopted children; these families are no less happy and these children no less loved than ours. I wish the best to all readers, no matter which route they use to expand their family. Any readers (especially in the New York/New Jersey area) who might be interested in more details about my experience should feel free to contact me through the Voice.

Barbara Kornfeld

Prodigy and Grateful Med

hose of you with computers that have a modem (telephone link) now have access to a myriad of databases with their special Bulletin Boards. Some of the larger ones include Dialog, Nexis, American Online, CompuServe and Prodigy. There is even a magazine, *Online Access*, whose May cover offers articles on Adult Boards (KinkLink), Shareware, Police Net, and the phone numbers for over 5,000 Bulletin Boards.

One of our Los Angeles coordinators, Sherry Weinman, using Prodigy, ran a message on their Health and Lifestyle bulletin board: "I'm seeking others who are offspring of mothers who took DES during their pregnancies. I belong to DES Action (1615 Broadway, Oakland CA 94612), a non-profit support group that's been very helpful on a number of DES-related health issues..."

She also sent a note on the CompuServe "Forum" under the Self Help/Support Section. One respondent said that using these networks is especially helpful to those who live in remote areas. Another wrote, "I think that some of us may need to be reminded of the effects (long term) of using DES." A DES daughter in New Hampshire told her story of pregnancy problems. Another remarked that spreading the word on DES is not "the voice of doom and gloom" but "forewarned is forearmed," and that she is writing a book on her fight to have a baby.

Computers with modems also make it possible to tap into medical libraries. Our member

"Spreading
the word on DES
is not "the voice of doom
and gloom" but
'forewarned is
forearmed.'"

Martha A. Russell sends this information:

"Readers who have a personal computer, a modem, and communications software may be interested in learning about Grateful Med, a computer application which provides access to materials in the National Library of Medicine. Grateful Med has an easy-to-use on screen program which will prompt you for search terms. Then it will connect you to the NLM computer, enter your search request, and present you

with references to be copied. Users can then find journal articles in their medical library or order them through the mail. Grateful Med is easy to use and exists in forms for both IBM and Macintosh computers. The Grateful Med software costs \$29.95 and the average search is about \$3.00. Along with the software, the user also needs to acquire a password to use the NLM computer.

Order forms and further information may be obtained from:

National Technical Information Service, 5285 Port Royal Road, Springfield, VA 22161, telephone (703) 487-4650.

You can get further information from a report in *US News* and World Report of 5 Oct. 1992, "On-line medicine." This article discusses various ways for the lay person to become familiar with medical literature.

Use Donor Option at United Way

f you give to the United Way at your place of work, you can specify that your pledge should go to DES Action. DES Action and its local affiliates are not United Way agencies, but, as a health organization, we are able to participate in this Donor Option Plan. Simply find the line or the card marked "Donor Option" and write DES Action. If there is no line, or a card has been omitted from your packet, write in Donor Option—DES Action.

Not every county has a donor option plan. Contact your local United Way or ask your United Way representative for information about your county.

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.

A Cautionary Note on Possible Long-term Risk of Fertility Drugs

by Pat Cody and Judy Turiel

ny medical procedure carries risks, including risks we know about, such as infection from surgery, and those we do not know about—as DES turned out to have. DES daughters and sons know all too well the need to weigh potential risks, which may become known only years later, against benefits of a proposed fertility treatment.

Two recent medical reports suggest a possible increase in risk for ovarian cancer among women who had used fertility drugs, particularly medications that stimulate ovulation (or "superovulation" for IVF-related procedures). Dr. Alice Whittemore and colleagues analyzed 12 studies on invasive epithelial ovarian cancer cases diagnosed during the years 1956-1986. They concluded that pregnancy, breast feeding and oral contraceptive use each induce biological changes that protect against this type of ovarian cancer. They report that infertile Caucasian women who used fertility drugs had an almost three times greater risk for developing ovarian cancer than women with no history of infertility. The risk was highest among a sub-group of fertility drug users who never became pregnant.

However, this finding was based on very small numbers and Dr. Whittemore stated that it "is really very tenuous." The American Fertility Society found serious limitations in the study: data on fertility drugs was available in only three of the 12 studies, many

of the drugs were given for ordinary pregnancies before 1970, and differing protocols were used among the studies. Officials of the National Cancer Institute, according to the Winter 1993 newsletter from RESOLVE, "said that, based on this study, they cannot make any recommendation for physicians to change their practices regarding the use of fertility-enhancing drugs."

A second report on a different type of ovarian cancer—granulosa-cell tumors—was published in The Lancet of 17 April 1993. The authors described 12 patients with granulosa-cell tumors detected after infertility treatments of ovarian stimulation through the use of clomiphene citrate (Clomid) and/or human menopausal gonadotropins (hormones such as Pergonal that stimulate the growth of ovarian follicles). Granulosa-cell tumors account for 10% of all ovarian cancers, and are usually seen in patients between the ages of 50 and 59. In the cases studied, age at diagnosis ranged from 25 to 37. The authors write that "although the data do not prove the existence of a causal relation" between the gonadotropin drugs given and the tumor development, caution is warranted. They recommend that ovarian size be monitored by ultra sound before, during and after treatment. A "persistently enlarged ovary should be regarded as a potential neoplastic development (i.e., site for a developing tumor) until

"These reports do indicate the need for additional studies to determine whether or not the use of fertility drugs increases a woman's risk for developing ovarian cancer."

otherwise proven." The authors also urge establishment of a registry to study whether such drugs increase the risk of ovarian cancer.

All of these findings are preliminary. They do not demonstrate that fertility drugs cause or promote ovarian cancer. These reports do indicate the need for additional studies to determine whether or not the use of fertility drugs increases a woman's risk for developing ovarian cancer. Even as a preliminary "possibility", however, the potential unknown risk is a piece of information fertility patients may want to consider as they weigh benefits and risks in their own situation. For some women, for instance, a woman with a family history of ovarian cancer, a potential long-term risk may tip the balance against use of these drugs.

Whittemore et al, "Characteristics relating to ovarian cancer risk: collaborative analysis of 12 U.S. case-control studies," Am. J. of Epidemiology, Vol. 136, No. 10, 1992.

Willemsen et al, "Ovarian stimulation and granulosa-cell tumour," The Lancet 17 April 1993.

EDUCATION from page 1... from these individuals of not being able to find the simplest information about DES and in many cases knowing more about DES than their doctors."

DES Action has written letters of support for each of five proposals which were submitted, and we have been asked to participate in each funded project for our expertise in DES education. Applications have been received from California, Wisconsin, Texas, and the Northeast. Recipients of the grants will be announced in several months and the projects will begin October 1, 1993. Look for more details about the funded projects in these pages.

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In February the NCI issued an RFA entitled "Follow-Up of DES-Associated Clear Cell Adenocarcinoma." The RFA announced that 4-8 grants totalling up to \$850,000 over four years would be awarded this fall. In describing the background to this announcement, the NCI writes:

"Recent evidence has renewed

interest in the continued followup of CCA patients, who are just entering the at-risk age range for most of the hormonally-related tumors (e.g. breast)." They also cite the 19% clear cell cancer recurrence rate documented in the Herbst registry of clear cell adenocarcinoma (CCA) cases.

The primary objectives of the research are:

- 1) to continue follow-up of documented CCA patients and continue accrual of incident cases to further define the age-incidence curve, the survival rate, the recurrence rate, the incidence of second primary cancer(s), and the incidence of other health outcomes: and
- (2) in women with CCA, to ascertain data on exposure to DES, other hormones, and other relevant factors, and to assess the determinants of survival, recurrence, and other health outcomes.

The RFA also notes that: "Congress expressed its concern in the FY 1992 appropriations bill with the following language: "The Committee is concerned that despite scientific

cause to investigate, DES research has declined. The Committee intends for longitudinal studies of the DES-exposed to be a priority of the NIH." The FY 1993 Senate Appropriations Subcommittee Report states, "NCI is expected to work closely with organizations representing DES victims in developing and implementing the national education programs and longitudinal studies mandated by [this] legislation."

Renew Now and Save

ffective 1 October, we will increase our membership fee from the present sliding scale of \$25–50 to \$30–60. This is our first increase since 1989. We still have the lowincome fee of \$10. If you've received a renewal letter lately, you may want to renew now at the old rates. You can tell when your membership lapses by the number in the upper right corner of your mailing label; this is issue 57, Fall is 58, and so on.

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Breast Cancer Risk for DES Mothers

n 1984, the first major study of breast cancer risks for DES mothers was published in the *New England Journal of Medicine*. We reported on that research in our Winter 1985 issue, noting that DES mothers had a 40-50% greater risk than non-exposed mothers. Now the same researchers have done a follow-up (through June 1989) and report on it in the *Journal of the American Medical Association* for 28 April 1993.

The pattern they saw earlier has not changed much. They surveyed 3,029 DES mothers and 3,029 non-exposed mothers from four major medical centers. In every age bracket, there was more breast cancer in the DES exposed than in the nonexposed, with the largest increase in the over-60 group.

Their conclusion: "Exposure to DES during pregnancy is associated with a modest but statistically significant increased risk of breast cancer." The risk is 35% greater—somewhat less than the risk given in the 1984 report.

To put this in perspective: even though mothers have a greater risk, the numbers are still small: 185 cases out of 3,029 or 6.1%. That means 93.9% of the DES mothers studied did not develop breast cancer. Breast cancer is the leading cancer for

women in the U.S., and all women need to do monthly breast self-exam and, for those over 50, have an annual mammogram and physical breast exam by a health professional. Recommendations for DES mothers are the same.

Do YOU need more information on breast cancer?

Order DES's booklet *Breast Cancer* today. It summarizes findings on risk, protection, detection, and treatment. Only \$2.50. Send check or money order to DES Action.

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