

DES Research Update 1999 Conference

By Sally Keely, DES Action Board Member

THE DES Research Update 1999: Current Knowledge, Future Directions Conference was held in Bethesda, Maryland last month. Sponsored by the National Institutes of Health, the Centers for Disease Control, and the Public Health Service Office of Women's Health, this meeting was a sequel to the 1992 NIH Workshop on Long-Term Effects of Exposure to DES. Congresswoman Louise Slaughter, co-sponsor of the DES legislation signed into law last October, gave opening remarks.

Research overviews were presented by Arthur Herbst M.D., Robert Hoover M.D., Retha Newbold, and Deborah Wingard, Ph.D. Dr. Herbst, who discovered the link between DES in-utero exposure and clear cell cancer in 1971, updated us on the clear cell adenocarcinoma registry statistics. There are now 715 women included (62% of whom have documented DES exposure), with an age range of 7-48 at time of diagnosis. He noted that there are more cases in the 40-46 age group than the

35-39 age group, suggesting a possible second peak of incidence of clear cell adenocarcinoma.

"Clearly, the need for continued education of medical professionals is vital."

Dr. Hoover, Director of Epidemiology at NCI, presented some of the current health implications of DES exposure. The only studied risk to moms is a 30% increased risk of breast cancer. No new information on daughters, but he did stress that we need to continue to study the incidence of breast cancer as we age. As for DES sons, he reported that some studies show significantly increased risk of testicular cancer and others show increased risk but not significantly. No studies have shown significantly increased infertility in sons. He reported that questions on 51 potential auto-immune disorders have been included in the DESAD cohort questionnaires. Significant differences have been seen between exposed and non-exposed for the following diseases: 5-fold risk of Hashimoto's thyroiditis, 3-fold risk of pernicious anemia, and 3-fold risk of rheumatoid arthritis.

Ms. Newbold, Head of the Endocrinology Section of the

Toxicology Lab at the National Institute of Environmental Health Sciences, spoke about the latest mouse studies. As we have reported in recent issues of the VOICE, 3rd generation DES exposed mice (DES-grandchildren) have an increased occurrence of tumors, but no problems with fertility.

Dr. Wingard, Professor at the University of California at San Diego, spoke about education and outreach. A recent questionnaire showed that only half of ob/gyns knew that ectopic pregnancies and miscarriages could be related to DES exposure and only 11-21% knew that women who took DES are at increased risk of breast cancer. Clearly, the need for continued education of medical professionals is vital.

Four breakout sessions presented a unique opportunity for researchers, medical professionals, legislators, public health officials, consumer advocates, and DES exposed persons to come together and share concerns. Breakout topics included clinical research, epidemiology, basic research, and education/outreach. The goal of each session was to establish the two most important DES issues, thus making eight issues when we reconvened. I was intrigued at how much commonality there was among the groups and

continued on page 8...

I N S I D E

Honors

p. 3

DES Advocacy Program

p. 6

Fall 1999 Symposium

p. 7

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 0607
Univ. of Calif-S.D.
La Jolla, CA 92093
Box 661653
Los Angeles, CA 90066

5835 Terrazo Court
San Jose, CA 95123

Colorado

P.O. Box 2645
Colorado Springs, CO 80901

Connecticut

196 Weatherly Trail
Guilford, CT 06437-1203

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

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

3708 Rodale Way
Dallas, TX 75287

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
Reseau—DES France
44 Rue Popincourt
75011 Paris

DES Action

Ireland
16-20 South Cumberland Street
Dublin 2

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 Online: Two new DES support e-mail listservs!

INTRODUCING online support for DES sons: A DES son in Oregon has recently started an online support forum for DES sons including an email listserv. Michael Freilick, DES Sons Network Coordinator, serves as a consultant to the list. To subscribe, send email to des-sons-request@egroups.com To access the website, visit <http://www.egroups/groups/des-sons/>. First time users will need to register with egroups.

Introducing the new DES-FAMILY listserv: A member of the DES-daughters listserv has recently started a mailing list where all DES-exposed and their family and friends can share support and information via e-mail. To join, send email to listserv@sact.com In the body of the message write only the phrase "subscribe des-family" (without the quotes). You will receive a welcome letter back confirming your subscription.

And don't forget the DES Action listserv, DAL. DES Action members are welcome to join by sending e-mail to DAL-request@telelists.com In the body of the message write only the phrase "subscribe YourFirstName YourLastName" (without the quotes). Be sure you replace "YourFirstName" and "YourLastName" with the name under which your DES Action membership is listed. You will receive a confirmation request to which you simply hit reply and send. If you have any questions about DAL, feel free to e-mail the list owner, Sally Keely, at owner-DAL@telelists.com. continued on page 8...

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1615 Broadway, # 510
Oakland, CA 94612
ISSN 1522-0389
(510) 465-4011
FAX: (510) 465-4815
Hotline: 1-800-DES-9288
e-mail: desact@well.com
<http://www.desaction.org>

Executive Director:

Nora Cody

Board Officers

President: Kari Christianson
VicePresident: Michael Freilick
Secretary: Sally Keely
Treasurer: Stephanie Kanarek

Contributors:

Nora Cody
Pat Cody
Sally Keely

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DES Action Honors Four Outstanding Scientists

by Nora Cody

FOR many of us one of the highlights of the National DES Research Conference was the opportunity to honor four outstanding scientists, each of whom has demonstrated their commitment to DES research for over twenty years. On Monday evening, July 19, DES Action presented Distinguished Service Awards to Arthur Herbst, Robert Hoover, John McLachlan and Retha Newbold.

Dr. Herbst wrote the study, published in the New England Journal of Medicine in 1971, that first linked DES exposure with clear cell adenocarcinoma of the vagina or cervix. He has since that time maintained the Registry for Research on Hormonal Carcinogenesis (Clear Cell Cancer Registry).

Dr. Hoover is the National Cancer Institute Director of the Continuation of Long-term Follow-up of DES-Exposed Study (formerly known as DESAD). He has advocated for DES research within the NCI for over twenty years, and for the inclusion of consumer advocates in decision-making processes.

Formerly Science Director of the National Institute for Environmental Health Sciences, John McLachlan has studied the effects of DES in animal models for over twenty years. He now heads the Center for Bioenvironmental Research at Tulane/Xavier University in New Orleans. In 1997 Newsweek magazine named him as one of 100 "people to watch" for the new millennium.

Working with John McLachlan and others, Retha Newbold has taken the lead in studying multi-generational DES effects in the mouse model. Ms. Newbold is a scientist with the National Institute of Environmental Health Sciences, and recently published an important study that for the first time linked DES with "third generation" effects in mice.

Each awardee was presented with a plaque reading:

DES Action USA presents this Distinguished Service Award to (name of scientist) in recognition of his (or her) tireless dedication to research benefiting the lives of DES exposed individuals. Bethesda, Maryland, July 19, 1999. ■



The honored and the presenters, left to right: Mike Freilick, Vice-Pres., DES Action; Dr. Arthur Herbst; Retha Newbold; John McLachlan; Pat Cody, Program Director, DES Action; Dr. Robert Hoover; Nora Cody, Exec. Director, DES Action; Kari Christianson, Pres., DES Action.

DES Action's Speech at the National DES Research Conference

This is the speech delivered by Nora Cody on July 20 on the second day of the National DES Research Conference in Bethesda, MD

THIRTY years ago today man first walked on the moon. It was an incredible scientific achievement, inspiring to millions of people. The lunar landing showed the great potential of science and technology to show us the best humans could do.

Thirty years ago today DES was still being prescribed to pregnant women in this country and, indeed, around the world. By 1969 scientists had studied this scientific substance for over three decades. Over and over, they had found cancer in laboratory animals. In the famous Dieckmann study in 1953, they had discovered that DES was completely ineffective in preventing miscarriage and in fact more harmful than a placebo.

Yet for all of this scientific inquiry, there was a fundamental failure, and DES showed us the terrible potential for human tragedy from scientific discovery.

Today science offers, not a solution to the problems of the past, but a way to better understand and cope with the future. DES-exposed people that I have met by and large accept the fact of their exposure. What they will not accept is denial of their problems and limitations on research that keep us from learning the full scope of the effects of DES.

Fortunately, they do not have to accept such denial. Gathered here today are scientists willing to look beyond the established

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wisdom and explore what might be; to open their minds to all of the possible ramifications of DES exposure.

For years now we have received calls, with increasing frequency and urgency, about the possibility of multi-generational DES effects. DES daughters and sons with their own children, or the grandmothers, call and worry about health problems their children are experiencing, or might experience. And for years nearly all doctors and certainly most scientists dismissed the possibility.

Not Retha Newbold, who spoke so eloquently yesterday. She and John McLachlan have worked to understand DES for more than twenty years. Their research on mice does not answer the question about third generation effects on humans. But it does confirm the relevance of such research.

We call upon the NIH to allocate the necessary funds to sufficiently survey the DES grandchildren and upon the scientific community to devote their attention to this subject, so that we may begin to resolve this question. This issue is not only important to the DES-exposed, but as our friend Theo Colborn would no doubt point out, it has significant ramifications for our

overall understanding of other endocrine disrupters.

Last night DES Action honored Retha and John McLachlan, Dr. Bob Hoover, and Dr. Arthur Herbst, for their longstanding devotion to DES research. Each has studied DES for over twenty years. Each has remained committed while DES research went in and out of fashion.

Dr. Herbst, with his determination to continue the clear cell cancer registry, has shown the world that there is no upper age limit for clear cell adenocarcinoma of the vagina and cervix. There remains a great deal to understand about this cancer. We also have the challenge of educating many of our health care providers about the fact that their DES-exposed patients need to have the screening exam for clear cell cancer throughout their lives.

Dr. Hoover has expressed through his actions and his words his own personal commitment to continuing the long-term follow-up of DES-exposed and under his leadership the consumer community is now included at the decision-making table.

Our DES community has many concerns. As we age, menopause ranks right at the top of the list. As the final stage of the reproductive cycle for women, there is naturally high interest in whether menopause will be different for DES daughters. The anecdotal reports, and the general feeling, is that DES daughters are going through menopause much earlier than other women. We don't know if

this is really true. There has not been enough research.

Secondly, of course, there is concern about menopausal hormones. Is it safe to expose DES daughters to more hormones? No one knows, yet most doctors are quick to reassure women that these hormones must be safe because no harm has been shown. Well, as far as we know, no one has studied this question so we can equally assert

"I must speak as well about DES sons and DES mothers, the poor stepfolks of the DES population."

that safety has not been established either. Meanwhile, as we wait, DES daughters must daily confront and make a very difficult personal decision.

I must speak as well about DES sons and DES mothers, the poor stepfolks of the DES popu-

lation. There has been a longstanding neglect of research on the sons and the mothers, and we are eager to learn the results of the long-term follow-up studies. It may be that certain effects on males, such as an increase in prostate cancer, will only be clear as the population ages. But we must make sure that we continue to adequately monitor and investigate all segments of the population so that all effects can be detected.

There is another ironic contrast that occurs to me as I think about what happened thirty years ago today. And that is in the vast resources the U.S. government put into NASA, and the effort to be the first to land on the moon. And then to realize that our government has never conducted even a small national education program to inform the public about DES. We hope to change that in short order.

In 1992 DES Action and the DES Cancer Network worked to pass legislation mandating such a

program. The NCI conducted a pilot program with five sites around the country. We went back in 1997 to once again attempt to have Congress mandate a truly national education program, aimed at both health care providers and the public. This legislation passed at the end of last year, and we are still waiting for a plan and a program. We will continue to press for the kind of outreach and education we believe to be necessary to serve the DES community.

We are thrilled to be here and to participate fully in this important meeting. We hope that this meeting sends the message that DES research is important, it is happening, it must and will be funded. We applaud the co-sponsors for their interest and support for this meeting, and look forward to a long and fruitful continued collaboration. ■

DES and the Millennium

Yes! There is a connection!

The turn of the century and millennium will probably mean that many doctors, hospitals and pharmacies will clear out their 20th century files. A leading DES attorney, Aaron Levine of Washington D.C., advises DES-exposed people to try to get medical records of their exposure before records are lost.

You may not plan now on any law suits, but you may change your mind. Also, in order to be part of any research project, you need proof of exposure. If you would like our information sheet on getting medical records, send us a stamped addressed envelope.

National DES Advocacy Program: Report from Washington, D.C.

DES Action meets with
National Cancer Institute
Director

It was a heady and intense few days for the DES Action staff and Board members who stayed on in Washington, D.C. after the NIH Conference. While the conference was wonderful, we remained concerned about the National Cancer Institute's commitment to adequate funding for DES research. In addition the NCI is now collaborating with the Centers for Disease Control on plans for the National DES Education Program, and is expected to provide most of the funding for such a program. However, the amount of funds for the education program remains unresolved and we needed to do everything we could to press for enough funds to carry out what is necessary.

Here is a roundup of what happened.

On Wednesday, July 21 we met with Dr. Wanda Jones, Director, Office of Women's Health of the Department of Health and Human Services, and with her staff members Susan Wood and Suzanne Haynes. Dr. Jones spoke at the DES Research Conference and has been a strong advocate for DES research. We discussed ideas for DES research the National Cancer Institute might fund. They expressed their strong support, although their office can only advise and cannot compel agencies to act.

Later on July 21 we met with aides to Senator Tom Harkin Bryan Johnson and Peter

Reinecke. We urged them to get involved and to convey the Senator's strong priority for DES research and education to the NCI, and they agreed.

We also met with Cindy Pellegrini, aide to Representative Louise Slaughter. Cindy understands our concerns and expressed the willingness of her office to become involved as well. Rep. Slaughter has been a leader for DES research in Congress.

"As Director of the NCI, Dr. Klausner controls a budget of over \$2 billion. We face the challenge of competing with thousands of other pressing cancer-related issues for his attention."

After meeting with Cindy we spoke with an aide to Representative Patsy Mink, a DES mother. He agreed to speak with Rep. Mink to see if her office will also support increased funding for the DES education program.

On Thursday, July 22, DES Action staff and Board members met with Dr. Richard Klausner, Director of the National Cancer Institute. Eager to present our concerns to Dr. Klausner, we asked for and were granted this meeting with just one day's notice.

As Director of the NCI, Dr. Klausner controls a budget of over \$2 billion. We face the challenge of competing with thousands of other pressing cancer-related issues for his attention.

Our goals for our thirty minute meeting were to raise the profile of the DES issue on Dr. Klausner's radar screen, to present our case for adequate funds for DES research and education, and to establish a good relationship. We believe that we accomplished these goals.

We began the meeting by presenting the following points:

1. Reminded Dr. Klausner of the numbers of exposed, and the NCI's obligation to study and help the 10 million Americans exposed to DES.
2. The DES-exposed population represents a unique opportunity, that must not be lost, to study the biology of estrogenization on men and women - a large and willing population. Many DES daughters are now entering menopause, a reproductive watershed that may provide valuable new information as we examine the interaction between changing hormone levels and DES exposure.
3. Additionally, new evidence from NIH studies on third generation animals shows the biological basis for estrogens inducing genetically transmitted disease. This research must be followed with studies of humans, before it's too late and the population is lost to research.
4. We need a broad-based, comprehensive program of consumer and provider

continued on page 7...

DES Action's Fall 1999 Symposium

ON October 16 DES Action members will convene in Plainview (Long Island), New York for a day packed with information and networking. This year we are thrilled to have an excellent roster of speakers and workshops to offer. Our keynote speakers:

- **Retha Newbold, Ph.D.**, National Institute of Environmental Health Sciences, is the lead author of the report "Increased Tumors but Uncompromised Fertility in Female Descendants of Mice Exposed Developmentally to DES," which described a 'third generation' effect in mice exposed to DES. *Dr. Newbold will describe the*

results of her research and the implications for human health.

- **Phyllis Mansfield, Ph.D.**, is professor of Women's Studies and Health Education at Pennsylvania State University and Director of the Tremin Trust Research Program on Women's Health, a longitudinal, intergenerational study of women's health and menstruation that has been going on since 1934. *Dr. Mansfield will speak on the menopausal transition.*
- **Candy Tedeschi, R.N.C.**, OGNP, Coordinator of DES Screening Center, Long Island, NY. *Candy will present the latest research*

data on DES mothers, daughters, and sons from the "Continuation of Long-term Follow-up of the DES-exposed" study.

In addition to the speakers, the day will include a series of workshops that will be repeated (i.e. everyone will be able to attend two different workshops).

Workshop topics are:

1. Infertility/Reproductive Technologies and DES
2. Menopause: Hormones, alternatives, and you
3. Legal issues: what does it mean to pursue a DES lawsuit?
4. General medical concerns (including auto-immune effects and DES sons).

continued on page 8...

REPORT FROM WASHINGTON from page 6... education, and we must have adequate resources to carry out the recommendations of the conference. The 5 small pilot projects cost almost \$6 million, or nearly \$2 million per year. We need at least that amount of money to do a national DES education program.

Dr. Klausner responded to our presentation by stating that (here I paraphrase):

1. He agrees that the DES-exposed population is a valuable resource and must not be lost or neglected. He met with Dr. Robert Hoover (Director of the Long-term Follow-up of DES-exposed study) and Dr. Ken Buto on July 21 to discuss the cohort studies

and ideas for research. Ken Buto is interested in molecular epidemiology - studying some of the questions, e.g. biomarkers and estrogen imprinting, discussed at the meeting. We have a strong advocate in Dr. Robert Hoover. **The NCI is committed to funding the cohort studies.**

2. In terms of the education program, \$6 million is a lot of money. The entire communications budget of the NCI is only \$12 million. In the past NCI Directors have just thrown money at problems; he's more interested in results.

We were joined at the meeting by Dr. Sidney Wolfe, director of the Health Research Group and a well known consumer health

advocate. He recounted, briefly, his long involvement in DES, which includes pushing for and serving on the two federal DES Task Forces (one in 1978 and the second in 1985). He talked about how the history of this issue is that interest wanes and we have to come back and kick up a fuss. He is ready and willing to help raise the profile of the DES issue.

Overall, the meeting went well. We did not expect to get a financial commitment right now, and we will have to wait and see what materializes in terms of dollars for DES research and education. I know that we can count on DES Action members to get out their letter-writing pens if necessary, to continue to pressure the National Cancer Institute to give DES research and education the priority they deserve. ■

DES RESEARCH UPDATE from page 1... participants. Major concerns included the following:

- further study needed on ramifications to DES sons and the 3rd generation,
- continued follow-up of the established cohorts (groups of mothers, daughters, and sons currently being studied),
- concerns about other hormone exposure such as hormone replacement drugs, fertility drugs, and oral contraceptives,
- establishing biomarkers that could measure exposure and genetic effects,
- coordinating education efforts, and
- disseminating information to providers and consumers.

Between sessions, attendees perused about 20 posters describing various research studies. Researchers were available for questions. Some of the posters were previews of papers expected to be published in the near future. Watch the VOICE for reviews! ■

DES ONLINE from page 2...

There is also an online support group for DES daughters, DES-L, hosted by TASC - The American Surrogacy Center. The purpose of this listserv is to provide support and exchange information with other DES daughters via the internet. To read more about the DES-L listserv and to join, visit the webpage at http://www.surrogacy.com/online_support/des/. ■

1999 SYMPOSIUM from page 7...

The Symposium will be held on Saturday, October 16, 1999 at the Marriott Residence Inn in Plainview, New York. The cost is \$85, which includes all registration materials and lunch. We need your registration and check by September 15.

There are a limited number of rooms set aside at the Marriott. If you need to stay at the Marriott hotel, call the hotel at 516-433-6200 no later than September 15 and reserve your room. Tell them you are with the DES Action group to receive the reduced room rate of \$135 (single or double). ■

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A N N I V E R S A R Y

National Office

1615 Broadway, Suite 510
Oakland, CA 94612
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