

DES ACTION International Colloquium



30 Years of

Discovery
Education
Science

April 2, 2001 ■ B-339 Rayburn Building, Capitol Hill, Washington, D.C.

APRIL 2001 will mark thirty years since the publication of the landmark article "Adenocarcinoma of the Vagina: Association of Maternal Stilbestrol Therapy with Tumor Appearance in Young

Women." This article, written by Dr. Arthur Herbst, et al, and published in the *New England Journal of Medicine*, linked cancer in young women to their in-utero exposure to DES and

brought about an end to the use of DES during pregnancy.

The DES experience exploded the scientific concept of the placenta as an impenetrable barrier

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Update on DES Internet Listservs

by Sally Keely (aka "DESxposed")

THERE are now several DES e-mail lists that you may be interested in joining!

DAL, the DES Action Listserv, is exclusively for DES Action members. This list is primarily informational and provides a direct link between DES Action staff and our members. To subscribe, send e-mail to DAL-request@telelists.com with the command "subscribe YourFirstName YourLastName" (without the quotes) as the only thing in the body of the message. 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 problem, e-mail DALowner@telelists.com.

DES daughters should check out DES-L, the DES daughters listsev and online support forum at http://www.surrogacy.com/online_support/des/ To join the listserv, complete the online application and get ready to share support and information with 1000 other DES daughters!

DES sons will want to join the DES-Sons list for confidential discussions of issues related to DES exposure in males. This list was developed in conjunction with the DES Sons Network of DES Action. To subscribe send

blank e-mail to des-sons-request@egroups.com. Direct questions to des-sons-owner@egroups.com.

The DES-Family list welcomes all DES-exposed, their family, and friends. To join, e-mail listserv@sact.com with only the command "subscribe des-family" (without the quotes) in the body of the message.

Charli@egroups.com can help if you have questions.

Lastly, announcing the newest DES related listserv, DES-Pregnancies. DES daughters who are pregnant, trying to conceive, or contemplating pregnancy are invited to join via the list website <http://www.onelist.com/subscribe/despregnancies>. You will need to register with onelist, if you aren't already. Contact ladonnakat@aol.com if you have trouble subscribing.

Now, happy chatting!

DES Action Affiliates and State Contacts

DES Action Affiliates

Each affiliate was created and nurtured by volunteers. Write to them if you want information or would like to volunteer.

DES Action USA National Office
610-16th Street #301
Oakland, CA 94612
desact@well.com

DES Sons Network
104 Sleepy Hollow Place
Cherry Hill, NJ 08003

DES Third Generation Network
Box 21
Mahwah, NJ 07430
Des3gen@aol.com

DES Action San Jose (California)
5835 Terrazo Court
San Jose, CA 95123

DES Action Massachusetts
P.O. Box 126
Stoughton, MA 02072

DES Action Minnesota
12445 Drake St., NW
Coon Rapids, MN 55448

DES Action Pennsylvania
Box 398
Nescopeck, PA 18635

DES Action Washington
719 15th Avenue, East
Seattle, WA 98112

State Contacts

State contacts participate in national projects organized by DES Action. Contact the national office if you would like to find out about our national projects.

Arizona
Los Angeles, CA
San Diego, CA
Grand Rapids, MI
New Jersey
New Mexico
Ohio
Oregon
Texas

DES Action International

Australia
Belgium
Canada
England
France
Ireland
The Netherlands
New Zealand

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COLLOQUIUM from page 1...

and has enlightened other important fields of science. Scientific knowledge about DES is pivotal to the growing field of endocrine disruptors and the understanding of estrogenic substances in our environment.

Scientists, environmentalists, and health activists can all learn from the ongoing experiment represented by humans exposed to DES.

The long term nature of DES effects, which are still being studied today, serve as a potent and living reminder of the harmful consequences of inadequate drug promotion and distribution. The DES experience is more relevant than ever before

in the new era of direct-to-consumer-advertising of pharmaceuticals.

To mark this important anniversary, DES Action will hold an International Colloquium on April 2, 2001 in Washington, D.C. All members of DES Action are warmly invited to attend. There is a registration fee of \$65, which includes all conference materials, lunch, and a networking reception. For those able to stay, there will be a day of visits to legislator's offices on Tuesday, April 3. Visit with your Congressional representative and tell him or her why continued funding for

DES research is so important!

For those traveling from out of town, we have reserved a block of rooms at the Hotel Lombardy, located at 2019 Pennsylvania Avenue, N.W., Washington, D.C. You can reserve a room by calling the hotel at 1-800-424-5486 or 202-828-2600. Tell the hotel that you are with group #8290. You must reserve your room by February 15, 2001.

Anyone interested in attending the Colloquium should contact DES Action at 1-800-DES-9288 or by emailing to desact@well.com. We will send you more detailed information and a registration form. ■

Opening Remarks: Senator Tom Harkin (D-IA) • Representative Louise Slaughter (D-NY)
(invited speakers)

Panels

I. Discovery: a Medical Myth is Shattered.

The place of DES in modern medical history will be explored by panelists who were pioneers and who continue their leadership in the ongoing discovery of the health effects resulting from DES exposure.

- Arthur Herbst, M.D., lead author of New England Journal of Medicine article and Director of the Registry for Research on Hormonal Carcinogenesis (Clear Cell Cancer Registry).
- Kenneth Noller, M.D., Principal Investigator, National Cancer Institute Long-Term DES Follow-up Study.
- Candice Tedeschi, N.P., OGNP, DES Screening Clinic, Long Island.

II. Education: Speaking Truth to Power.

Leaders in the effort to educate the public and health care providers, and to affect government health policy, will share lessons of success and the continuing struggle for full and fair funding.

- Sidney Wolfe, M.D., Director, Health Research Group, Public Citizen.
- Pat Cody, Program Director and Founder, DES Action USA
- Nora Cody, Executive Director, DES Action USA
- Susan Helmrich, Ph.D., Co-Chair, DES Cancer Network

III. Science: The DES Exposed as Sentinels and Sensors.

Key scientists in the field of endocrine disruptors are also experts who have studied DES in animal models for over twenty years. These speakers will explain DES in the context of the endocrine disruptor model.

- John McLachlan, Ph.D., Director, Center for Bioenvironmental Research at Tulane and Xavier Universities and Celia Scott Weatherhead and Albert J. Weatherhead III Distinguished Professor of Environmental Studies
- Carl Barrett, Ph.D., Scientific Director, National Cancer Institute
- Retha Newbold, M.S., National Institute of Environmental Health Sciences

International Roundtable: DES Action activists from around the world will give brief reports sharing stories and lessons from their organizing efforts.

Networking Reception: Immediately following the Colloquium a networking reception will provide opportunities for building lasting relationships to further the consumer health movement.

Letters to the Editor

Dear Editor:

As the coordinator of the DES sons e-mail support group, I want to share with you my wish for more discussions, a more lively forum, and just plain more insights and support.

I want to issue a request/invitation/challenge for each of us to dedicate our energy in the coming weeks to locate at least one additional DES son who can join this forum. If we did this, we would double the membership and the more we have, the more we can get the word out and reach still more members.

As I've learned from my own health changes over the years and also from the many of you who have written, DES has had a wide range of effects among all

of us. That's part of what makes it a medical challenge—the impact is diverse enough that few medical “generalizations” have yet been made about males and DES exposure. For some of us, the effects have been more pronounced in the areas of gender and sexual identity/psychosexuality. For others, it has been primarily physical in nature, if, indeed, we have experienced any impact at all that is clearly attributable to DES exposure.

The common challenge we face is to meet more DES sons, to learn more from one another, and to raise awareness in the medical and therapeutic communities of the diverse needs of DES sons. In turn, this can enhance

the financial commitment from groups like the National Institutes of Health toward future research about DES exposure in males.

I invite any of you who have ideas or suggestions of ways to gain more members for this forum to share your insights with the group by writing to des-sons@egroups.com. If you prefer, you can write to me privately at my general e-mail address of skerlin@teleport.com.

Scott Kerlin, Ph.D.
Host, DES Sons
Discussion Forum

DES Sons Home Page:
www.egroups.com/group/des-sons

Patient Protection

By Molly B. Spira
Borad Member, DES Action

CONGRESS is holding hearings on the Patient Protection Act of 2000, HR 5122—something all of us should be very interested in.

Up until this time, getting accurate and up-to-date information on physician and care-provider track records and malpractice information, regardless of whether you are a patient looking for a provider or a hospital granting privileges, has been nearly impossible. As someone who formerly credentialed physicians for a major Los Angeles hospital, I can tell you that many problem

physicians and care-providers slip through the cracks. NO system is fail-safe. State boards of medical quality assurance DO NOT share information with one another, nor is there any national oversight.

However, there is a national clearinghouse that compiles records on physicians who are deficient, the National Practitioner Databank. The American Medical Association has been successful, up to this point, in making that information closed to the public.

HR 5122, the Patient Protection Act of 2000, introduced by

Commerce Committee Chair Thomas Billey, would open that data bank to the public, over the internet.

Those who have access to the internet can visit <http://www.house.gov/commerce> and take a look at the proposed bill. You will need Adobe Acrobat (free from adobe.com). You will get information and testimony from the hearings. I encourage each of you to write your Congressperson to support HR 5122.

Why No Class Action?

By Patricia Stanford
DES Attorney, Jacksonville FL

MY purpose in writing this is not to give an exhaustive dissertation on class action law (about which hundreds of books have been written by many lawyers smarter than I!), but to give DES-exposed people some idea of how class action suits work...or in most cases don't work. There are many legal obstacles to class actions for personal injury or "tort" litigation, with more being thrown up by the courts everyday. While the federal system and most states still have class action law on the books, the courts hate to deal with it and as a result, class actions don't go very far. Of course, the one that everybody is watching now is the tobacco case here in Florida. But whether anything will actually come of it (that is, whether any of those plaintiffs get any money) is still a long shot.

To start with, there is a general rule against class certification in mass tort cases. There is a long line of cases involving everything from faulty pacemakers to bad hamburgers which have held that class action is an inappropriate device for the resolution of mass tort claims. The problem that the courts are concerned with would certainly be evident in DES cases. Unlike fen-phen or some other current cases, there were over 200 manufacturers of DES over the years it was made. Each of these companies has its own story to tell about where, when and how much it distributed (or didn't). Each individual has a unique exposure history, with different

brands, dosages, doctors, pharmacies, and levels of proof involved. And as you all know, there is a myriad of injuries linked to DES from cancer to pregnancy complications to infertility, let alone the potential for third generation and other claims. And within each subset of injuries, each potential plaintiff has causation and proof issues unique to her case. For example, in an infertility case, there may be alternative causation issues such as ovarian dysfunction (not DES-related), male factor, age, other medical conditions, and so on. It is the existence of these many individual issues that gives (actually requires) the courts to deny the class certification that must be granted before a class action suit goes forward.

Sindell v. Abbott Laboratories was a 1980 California case where a class action was attempted for a more limited class—DES daughters who had or might suffer clear-cell adenocarcinoma. The thinking was probably that by limiting the type of injuries to clear-cell, this class might avoid some of the arguments against certification. However, the court still refused to certify the class because of "the lack of commonality among class members on issues of proximate cause, extent of injury, and appropriate medical examination or treatment." It went on to write that "As a general rule, so-called 'mass accidents' or 'common disasters' are considered not appropriate for class litigation. This inappropriateness

is based upon the overwhelming uniqueness of the issues stemming from the necessity for the trier to hear and determine individually each victim's injuries, his suffering, financial loss, etc. Thus even though a common question may be involved (e.g. the defendant's wrong-doing), the matter is not suitable for a class action."

This is not to say that class actions don't have the potential for success. It depends entirely on the facts of the over-all circumstances. For example, with the current fen-phen class (and others involving Norplant and breast implants), there was only one—or a very small number—of manufacturers and the injuries linked to fen-phen use (at least the ones that are really being pursued in the suit) almost all involved the heart. However, the outcome of these huge cases is generally unfavorable in the end, besides taking an incredibly long time. The Norplant litigation has been going on for at least 5 - 6 years if not longer. What will probably happen is that the class will ultimately be split up and the cases will be sent back to the various states where the claims arose. And as we know from the breast implant experience - and maybe even with the tobacco class—class actions can often result in the companies seeking protection from the bankruptcy courts.

Believe it or not, individual suits offer the best likelihood of success, more privacy to you and your family, a higher settlement value, and a faster resolution. ■

Book Notes

Hormone Deception, by D. Lindsey Berkson.
Contemporary Books, 2000. 431 pp. \$24.95

By Fran Howell

THE cover is bland and the title, *Hormone Deception*, didn't grab me. Yet a glance at the table of contents sent me scurrying for chapter 4, The Canaries In The Mine. Of course I read it first, because it's rare to find anything written specifically about life as a DES daughter. Here is a first person account of how diethylstilbestrol exposure in the womb affected the author medically, and how it forged the direction of her life's work.

Describing the DES tragedy helps Berkson explain what she sees as the extreme problems caused by certain chemicals. Most of us, no doubt, are aware of the dangers posed by toxic compounds because the results are devastating and the correlation is easy. Thalidomide results in birth defects while lead poisoning wreaks havoc on medical and emotional development in children. But what Berkson so carefully details, using DES as a good example, is that some chemicals act as estrogens in our bodies, making them incredibly harmful. The problem in many cases is that it is difficult to test for estrogenic dangers, so it's easy for corporations, governments and individual consumers to ignore them.

Take, for example, phthalates, which are used to make plastics bendable. According to Berkson, the softer the plastic the more phthalates it has. Once inside your body, they disrupt

"The authors acknowledge that while most of us suspect the myriad of chemicals in use today are toxic, people generally feel safe because the federal government is regulating them. It's a misplaced trust and the book carefully explains why."

the way your normal hormones function. As DES daughters know all too well, when hormones in our bodies are out of kilter, lots of things go awry. It's such a certainty in this case that plastics makers have been taking phthalates out of products—especially baby pacifiers and teethers. But Berkson urges consumers to be wary of other items, especially kitchen plastic wraps and plastic containers which come in direct contact with food, and leach who knows how much in the way of chemicals into what we eat.

Hormone Deception does more than alert readers to dangers. It also details practical methods for getting as many toxins out of our lives as possible. Leave your shoes at the door to avoid tracking pesticides into the house, and open the bathroom window while taking a hot shower or bath, so chloroform in the chlorinated water isn't spread to your lungs through the steam. She's thought of it all, but acknowledges we can't eliminate all toxins from our lives because our environment is something of a chemical

soup. Instead, she urges us to each do what we can, within reason, to protect ourselves and our families.

Generations at Risk, by Ted Schettler, M.D., Gina Solomon, M.D., Maria Valenti, and Annette Huddle. MIT Press, 1999, 417 pp. \$17.95

By Fran Howell

WHILE shopping recently I came upon something I'd never seen before a bright blue, soft plastic loaf pan for baking. It looked interesting, consider the difficulties I have getting banana bread out of the pan. But I put it down instantly after reading that the product had been approved by the FDA. Having just finished *Generations at Risk*, I knew the FDA had probably not tested, or even looked at that pan before it went to market. Such a claim means very little, and in my mind sent up warning flags of potential serious problems.

The authors acknowledge that while most of us suspect the myriad of chemicals in use today are toxic, people generally feel safe because the federal government is regulating them. It's a misplaced trust and the book carefully explains why.

The first thing *Generations* does is debunk our belief that scientific examination of toxicity will give us accurate information for making public health decisions. Described in detail is how scientists make their determinations, and why their answers are tough to translate into practical health safety measures. The

Honor for DES Action Volunteer



Shirley Hoffman of Beachwood, Ohio, was inducted into the Ohio Women's Hall of Fame in ceremonies at the State Capitol in Columbus on October 24. We know Shirley, a DES mother, for her dedication to outreach and education on DES. She has also been active in her profession as a cytologist. The Hall of

Fame was created in 1978 to give public recognition to outstanding contributions made by Ohio women to their state, nation and the world. Members are honored for their "extraordinary commitment to excellence, achievement and service to others."

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authors maintain we cannot wait for scientists to deem a chemical dangerous with irrefutable proof. We as a society must decide when the evidence is persuasive enough to take action. Then, *Generations* explains exactly how to go about it.

There are chapters with step by step directions for assessing your exposure risks at home and at work. Then there is information for how to funnel that data to the proper authorities. This useful book then lists the addresses, phone numbers and web sites you'll need. Also included is information for medical practitioners to help in diagnosing potential poisoning cases. This is useful for patients too, who can give their doctors specific exposure related information which

may not be requested, but once offered, may point to an accurate diagnosis.

Generations is especially helpful for anyone worried about dangers posed by poisons in the environment. It clearly spells out, in easy to understand language, what to do when exposure risks to you and your family are higher than you will accept. Many of us are concerned but don't know what to do when faced with the massive tangle of governmental regulatory bureaucracies. The authors demystify it all, put things in perspective and offer clear cut suggestions for making the world a less polluted place. *Generations* gives readers the tools they need to take action, which is a wonderfully empowering feeling.

Taking Hormones and Women's Health: Choices, Risks and Benefits. National Women's Health Network, 514 - 10th St. Suite 400, Washington DC 20004. 134 pp. \$15.00

Reviewed by Pat Cody

THIS is the menopause book so much needed by all women. While it does not refer to DES daughters and mothers (that is not possible since no menopause research has yet been done on us), it has a wealth of information. The NWHN shares our philosophy of caution and the less medication the better. The authors write not only on risks and controversies on hormones, but also on "designer" estrogens, "natural" hormones, alternative approaches. We hope readers will lobby their public libraries to order copies of this valuable book. ■

Daughters and Infertility

THE *American Journal of Epidemiology* in its June 2000 Special Supplement published abstracts on papers presented at a meeting of the Society of Epidemiological Research held that month. Of special interest to us is the abstract on a forthcoming study, "Infertility among women exposed prenatally to diethylstilbestrol" by Julie Palmer and Elizabeth Hatch of the Slone Epidemiology Unit. Here are portions of that abstract.

"Although it is well-established that women exposed to diethylstilbestrol (DES) in utero have an increased risk of spontaneous abortion, ectopic preg-

nancy, and preterm delivery, it is not known whether they also have an increased risk of infertility. This question was assessed in data from an ongoing cohort study of 1,762 DES-exposed and 1,056 unexposed women. Participants were asked if they had ever tried to become pregnant for 12 months or more without success. If they had undergone evaluation for infertility, they were asked to give the diagnosis. A validation study indicated high agreement between self-report and medical record....

"More exposed than unexposed women had never been

pregnant.... and more exposed than unexposed had tried to become pregnant for at least 12 months without success.... DES exposure was significantly associated with infertility due to uterine problems, tubal problems, and more than one type of problem.... The present findings indicate that women exposed to DES prenatally have a higher risk of infertility and that the excess is primarily due to uterine and tubal factors." ■

22 YEARS OF

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