

Five New Studies on HRT

By Pat Cody

We are often asked if any studies have been done on, first, if DES daughters have a menopause that differs from that of non-exposed women, and second, whether any study has been done on DES daughters and Hormone Replacement Therapy (HRT) risks. The answer to these two questions is, no, no such studies have yet been done. However, we think that DES daughters, because of their exposure, may want to be even more cautious about HRT.

We hear from some DES exposed women that their doctors continue to encourage the use of HRT and downplay what new research shows. We wonder if these physicians keep up with the numerous studies being published. Our Fall 2003 issue #98 described reports on HRT and increased risks for breast cancer, and a small increase in cases of ovarian cancer. Since that issue, here are five new research articles:

- The *Journal of the American Medical Association (JAMA)*, on April 14 carried a report on "Effects of conjugated equine

estrogen in postmenopausal women with hysterectomy" from the Women's Health Initiative Steering Committee.

They are writing about Premarin (estrogen derived from the urine of pregnant mares, thus, Pre for pregnant and Mar for mares). The authors describe their objective as "to assess the effects on major disease incidence rates of the most commonly used postmenopausal hormone therapy in the United States." The women in the study came from 40 clinical centers, starting in 1993. They enrolled 10,739 postmenopausal women aged 50-79 with prior hysterectomy. Half of them got either conjugated equine estrogen (CEE) or a placebo.

What did they learn?

"The use of CEE increases the risk of stroke, decreases the risk of hip fracture, and does not affect CHD (coronary heart disease) incidence in postmenopausal women with prior hysterectomy over an average of 6.8 years. A possible reduction in breast cancer risk requires further investigation. The burden of incident disease events was equivalent in the CEE and placebo groups, indicating no overall benefit. Thus, CEE should not be recommended for chronic disease prevention in postmenopausal women." (*my emphasis*)

- On March 2 the National Institutes of Health ordered a stop to a large study on women

past menopause using estrogen only (not the more usual estrogen/progestin) because early results showed an increase in strokes.

- A separate, long term Nurses' Health Study showed that women past menopause who use either estrogen alone or estrogen/progestin pills have a much higher (2.29 times) risk for **asthma**. The *Journal of the American Medical Association (JAMA)* reported this in a February issue of its *Archives of Internal Medicine*.

- Also in February, the medical weekly *The Lancet* announced the stopping of trials in Sweden where HRT was given as menopausal treatment to women who had had breast cancer. The researchers learned that the HRT group has a much higher rate of a **new breast cancer occurrence**, and stated, "These findings indicated an unacceptable risk for women exposed to HRT...and the trial was terminated on December 17, 2003." This was the first study done on HRT in breast cancer survivors.

- Scientists working on **hearing** have found that their study of 32 women ages 60 – 86 who had HRT did from 10 – 30% worse on hearing tests than 32 women who had not received HRT. One of the lead researchers, Robert D. Frisina Ph.D. from the University of Rochester Medical Center, reporting on this finding at a February conference, said: "These results are very surprising. We thought hormones would help women hear better, because of the presence of estrogen receptors in the ear. This is the opposite of what we were expecting."

I N S I D E

We're Centenarian!

p. 3

100 Issues of the VOICE

p. 4-5

Spreading the Word

p. 7

How to Join the DES Daughters Listserv

DES Daughters should check out DES-L, the DES daughters listserv 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 1,000 other DES daughters! Note: this list is operated independently from DES Action.



Yes—I want to get answers about DES. Enclosed is my membership.

All members receive *The DES Action Voice* quarterly. Those at the \$100 level and above receive an annual report on DES Action's work and progress. All contributions are tax deductible.

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I am a: ☐ DES Daughter ☐ DES Son ☐ Other
☐ DES Mother of a: ☐ Daughter ☐ Son

DES Action USA

610-16th Street #301
Oakland, CA 94612
NM-1 VOICE

Name _____

Address _____

City/State/Zip Code _____

Phone () _____

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
Desaction@earthlink.net
www.desaction.org

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
www.desactionpa.org

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.

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(510) 465-4011
FAX: (510) 465-4815
Hotline: 1-800-DES-9288
e-mail: desaction@earthlink.net
www.desaction.org

Executive Director:
Nora Cody

Board Officers
President: Molly Spira
VicePresident: Michael Freilick
Secretary: Lisa Summers
Treasurer: Stephanie Kanarek

Contributors:
Pat Cody, Nora Cody, Fran Howell
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Sphinx Graphics, Berkeley, CA
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We're a Centenarian!

Celebrating 100 issues of the DES Action Voice

By Nora Cody

WITH this edition of the *Voice* we celebrate our 100th continuous issue of publication. For over 25 years we have been proud to serve the DES community with information about DES research and your health; with medical reports, legal news, and personal stories; letters to the doctor, book reviews, and more.

The premier issue was heavy on text (indeed, so dense it looks a bit like the proverbial fine print in a lengthy legal document) and filled with inspiring accounts of activist work around the country. The front page declared:

"This premier issue of DES ACTION VOICE is an important milestone in the growth of the movement towards public awareness about the health consequences of the use of Diethylstilbestrol (DES). This Newsletter is one tangible product of many individuals' dedicated efforts to make known on a national level the issues related to DES. . . .

"We of DES ACTION have chosen to call our National Newsletter the DES ACTION VOICE because we hope it will represent just that – the – *voice* to and for the DES exposed and those concerned about them, and the *action* to make the voice heard in solving problems arising directly or indirectly from DES exposure."

While we have made incredible progress on many fronts, what strikes me today is how

For over 25 years we have been proud to serve the DES community with information about DES research and your health; with medical reports, legal news, and personal stories; letters to the doctor, book reviews, and more.

little our mission has changed. We are still serving as the voice to and for the DES exposed; still using that voice to take action and solve problems arising from DES exposure; still seeking greater public awareness about DES.

To mark this occasion, we asked some longstanding members to submit anecdotes and statements about what the *DES Action Voice* has meant to them over the years. I'd like to share with our readers some of these tributes:

"When I was 21, I met Pat Cody in a Bay Area women's health and medical rights group – a big focus was simply getting ob-gyns to listen to what their women patients were telling them. It was about the same time that my mother phoned me to tell me that she had read articles about this drug called DES, which she had taken when she was pregnant with me. She was alarmed that it appeared to be linked to problems in the daughters of the women who had taken it, but tried to minimize the likely impact.

In the years that followed, I found myself educating doctors about DES, and having cryosurgery for dysplasia. By 1979, I was trying to get pregnant, and found Pat again through DES Action. I began taking *DES Action Voice* to doctor's appointments – it gave me a lot more credibility! After many problems (not all mine as it turned out), I finally had a full-term baby in 1983. He turned 21 yesterday, and I realize I have been remiss in not telling him about 2nd generation effects on men. It will be part of the next phone call, and I'll refer him to the website. I thank Pat and Nora for their perseverance and the *Voice* for its information and support from 1979 until today."

—Andi Biren, *DES Daughter*

"I became involved with DES Action in 1978 after learning I had a deformed uterus caused by DES. I looked everywhere for more information, wrote to the NIH and a doctor in Boston who was following DES daughters, and was told there were no differences in fertility between exposed and unexposed women. I felt as if I were in the eye of a tornado emotionally, and could find no other DES daughters having the same problem. I felt totally alone with this, as if no one else in the world had it but me.

One night I was listening to a radio talk show, and the guest was a DES mother. As a DES volunteer during that early time, I answered hundreds of phone

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100 ISSUES OF THE

DES Action Hosts Second Research Conference

On June 1, 1985, DES Action co-hosted a Conference on related research. Held at the University of California, the Conference was organized by Research Liaison, Judy Turiel, and DES Action's Cancer Research Liaison, Dr. William Wingard, an epidemiologist at the University of California, San Diego. With primary financial support from the National Cancer Institute, we were able to bring together medical researchers from Sweden,



THE DES ACTION VOICE
A FOCUS ON DIETHYLSTILBESTROL
Fall 1987

THE DES ACTION VOICE
A FOCUS ON
Winter 1997

Medical Reports on Fertility

by Judy Turiel, Research Liaison

With DES daughters at in-
a ran,

abnormalities associated with
prenatal DES exposure

THE DES ACTION VOICE

Medical Reports

Reviewed by Pat Cody

Report on Third Generation Male Mice

Fall 1989

"Proliferative lesions and reproductive tract tumors in male descendants of mice exposed developmentally to diethylstilbestrol" by Retha Newbold et al, Carcinogenesis No. 7, July 2000.

European DES Conference in

by Ellen 't Hoen, DES Aktiegroep, The Netherlands

Vous êtes née entre 1941 et 1971?



Were you born between 1941 and 1971?



ARE YOU HAVING INFERTILITY PROBLEMS?
ARE YOU HAVING REPEATED MISCARRIAGES?
ARE YOU HAVING PREMATURE DELIVERIES?
IF SO, IT COULD BE RELATED TO THE FACT THAT YOUR MOTHER MAY HAVE TAKEN DES DURING PREGNANCY.

1979

DES ACTION VOICE!

5 VOICE

THE
DES
ACTION

VOICE

A FOCUS

VOICE

Mouse Study Shows Link to Third Generation Effects

Reviewed by Molly Berigan Spira

A FOCUS

ON DIETHYLSTILBESTROL

Fall 2002 • #94

Increases Risk of Breast Cancer in Daughters

then raised to
"Prudence dictates
that men prenatally
used to DES, with
r disproportionately
high prevalence of
rogenital anomalies,
be considered an at-risk
population for
malignancies until
proved otherwise."

DES ACTION VOICE

DIETHYLSTILBESTROL

medical report

Patterns for DES Sons

Lawsuit Won on Pregnancy Failure

Andrea Goldstein, DES Action National Board member from Boston, was awarded \$50,000 in damages against Lilly for injuries related to her DES exposure. After three days of deliberation at the end of a four week trial, the jury decided on December 13, 1984, that one of Andrea's ectopic pregnancies and her T-shaped uterus were caused by her DES exposure. In the such verdict in the pregnancy was negligent in not providing adequate warning to prescribing physicians on the potential effect of DES on the unborn children of mothers who used it." Goldstein, a DES daughter, suffered two ectopic pregnancies and was found to have the T-shaped uterus made many DES daughters.

CONGRESSIONAL RECORD

DES AWARENESS WEEK

HON. TED WEISS

OF NEW YORK

IN THE HOUSE OF REPRESENTATIVES

Thursday, April 21, 1983

● Mr. WEISS. Mr. Speaker, I rise to support DES Awareness Week, April 18-23, 1983. DES ACTION, a national organization dedicated to educating the American public about the uses and consequences of diethylstilbestrol (DES), has designated this week as a time to locate and educate the many women and men who have no knowledge of their exposure to this potentially dangerous drug.

Between 1940 and 1971, doctors pre-

medical community witnessed a dramatic rise in the incidence of a rare vaginal and cervical cancer in young women whose mothers had received DES-related drugs during pregnancy. Subsequent medical research revealed a strong connection between DES and cancer of the reproductive organs. In addition, benign abnormalities throughout the reproductive tract have been documented in DES daughters. Because the DES daughter and son cohort is relatively young, the increased risk on their life cycles cannot yet be fully evaluated.

As a result, careful gynecological and urological monitoring may be necessary for these young women and men. Indeed, DES daughters are advised to have regular and sometimes special gynecological observation and exams. Their current physicians need

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Creating DES Awareness: A National Campaign

by Linda Usdin, National Media Coordinator

2004

Spring 2004 • #100

CENTENARIAN from page 3...

calls on the hotline we started in Massachusetts. On the national level I worked with DES Action so everyone would know what this drug did, and that DES daughters did indeed suffer from infertility more than the non-exposed. In the early 1980's research information began to trickle out confirming what I had known all along.

My journey with DES Action continues to this day. I served on the board of directors for 16 years, and still volunteer after 25 years. DES Action saved my life; it gave me the outlet I needed when I didn't know if life was worth living. We have accomplished so much in such a relatively short amount of time. But the fight is not over, and my affiliation with DES Action will continue for the rest of my life."

—Andrea Goldstein,
DES Daughter and former
Board member

"DES Action is the only place, with the sole exception of Mother Jones Magazine, that I have seen 100% accurate information on DES. Every other book or article or web site has something that is not completely true. DES Action is the place to go for the facts and for help."

—Isabel Auerbach,
DES Daughter

"DES Action has been an important part of my life for 26 years. So many of the people I have met have become lifelong friends. I remember that in one of our early mission statements, our goal was to put ourselves out of business by 1990. We thought that by that time everyone would have been

identified, been given expert medical care, and government agencies would be monitoring future risks. How naive. We didn't even think about third generation. Today as I look back at the first issue (yes, I still have them all) I had to smile because in many ways nothing has changed. The *DES Action Voice* is still the best, and in many cases the only, source of up to date information on DES issues. Keep up the wonderful work."

—Libby Saks,
DES Mother and former
DES Action Boardmember

"When I learned that I was a DES daughter, I was a young woman in college. The potential consequences made me feel frightened and alone.

Then I discovered the *DES Action Voice*, which became my lifeline to important information and resources. I began to feel part of a larger community.

Years later, one of my children was born premature and disabled. With the support of the wonderful staff and volunteers of DES Action, I co-founded the DES Third Generation Network, which has tried to be a resource for DES-exposed patients like myself.

Living with DES has not been easy, but the people of DES Action have touched my heart and provided support on my journey."

—Elizabeth Levine Wandelmaier,
Co-founder, DES Third
Generation Network

"DES Action, and its publication *DES Action Voice*, have played a crucial role in helping me to advocate for my health care. I have been a member of

DES Action for over 25 years, initially as a gift from my mother when I was a teenager. The information provided by them has allowed me to find the proper doctors and the proper health care as I continue on the journey that DES started me on before my life even began. Without DES Action, I would not be nearly so well informed, nor have such a wealth of understanding about the health effect of this drug."

—Kim Mazeres,
DES Daughter

"Having joined DES Action in its infancy, I've had an opportunity to meet many new friends with whom I share the trials and tribulations of the exposed. It's been an empowering experience and I am indebted to all those dedicated people, who work tirelessly to provide us with support and have brought our concerns to the research community. Thanks, DES Action, for all you do!"

—Robin Hertzberg,
DES Daughter

We always need the
names of physicians
who are informed
about DES
and sensitive to the
needs of their patients.
If you have such a
referral, let us know!

You've Helped Us Spread the Word

By Fran Howell, Board Member

If you got a phone call and a stranger on the other end of the line asked you to talk in public about one of your most personal matters, what would you do? Dozens of DES Action members were put in that spot during the past year and most all of them – incredibly – said, “yes!”

As DES Action media coordinator during implementation of the Centers for Disease Control and Prevention's DES Update, I found myself making those calls. In order to interest reporters in writing DES stories, I had to locate people in various cities to be profiled. So I often found myself on the phone, calling

members and asking for their assistance.

I remain astonished at how willing so many of you have been to help. Our stories are not easy to tell. Who wants to talk publicly about their own cancers, miscarriages, infertility, autoimmune issues and worries about 3rd generation children? To do so in the glare of TV spotlights is almost unimaginable! To do so to a reporter whose newspaper will land at the doorstep of neighbors, friends, bosses, and those you carpool with, is awesome!

So why did so many of you do it? Because we've all come to learn, through the years, that the DES story must be told. People

who were reluctant at first, realized the importance of getting information about DES into the media, and their stories turned out remarkably well.

Most of the reporters who wrote about DES were shocked at what happened, and questioned why they hadn't heard about it before. To be honest, I couldn't give them a good reason. So we keep plugging away at it.

Why get the word out? Because people who were exposed must be vigilant about their own health care – to catch cancers early, demand high risk obstetric care when pregnant, and factor in their exposure when making decisions about HRT use, which

continued on page 8...

Our Members Made It Happen

PHOENIX, AZ
KPHO-TV
Kathy Weiner

LOS ANGELES, CA
KCAL/KCBS-TV
KABC-TV
LA Daily News
Patti Negri & Marilyn Shenker

SAN FRANCISCO, CA
KRON-TV
Nancy Netherland & Pat Cody

BOULDER, CO
Boulder Daily Camera
Ginny Bank & Rose Moniak

FT. COLLINS, CO
Weird Sister West
Pat Cody

FT. MEYERS, FL
WBBH-TV
WINK-TV
Cathy Harris

ATLANTA, GA
Atlanta Journal Constitution —*Shirley Whitehead, Denise White & Julie Whitehead*

CHICAGO, IL
Chicago Daily Herald
WBBM-TV
Mary Damer & Kathryn Moran

CRAWFORDSVILLE, IN
Journal-Review
Beth Griffin & Cindy Hartwood

BOSTON, MA
Boston Globe South
WBZ-TV
Andrea Goldstein

KANSAS CITY, MO
WDAF-TV
Becky Burton

ST. LOUIS, MO
KMOV-TV
Chris Strezembosz

RENO, NV
KOLO-TV
Reno Journal Gazette
Kim Mazeres

AKRON, OH
Akron Beacon Journal
Jennifer Fenderbosch & Litsa Varonis

BETHLEHEM, PA
Express Times
Pam Capuano & State Senator Lisa Boscola

PHILADELPHIA, PA
Philadelphia Inquirer
WGTW-TV
Robin Hertzberg, Michael Freilick & Karen Mills

CHARLESTON, SC
WCIV-TV
Debra Lybrand

HOUSTON, TX
KHOU-TV
Sarah Ellenzweig

SALT LAKE CITY, UT
Deseret News
Molly Spira & Ramona Rudert

SEATTLE, WA
Seattle Post Intelligencer
Anne Leavitt & Claire Bloom

USA TODAY
Margaret Braun, Susan Helmrich, Susan Wood & Michael Freilick

WASHINGTON POST
Chris Vanselous, Jill Murphy, Lisa Summers, Carol Perry & Dana Beyer

BELO BROADCAST SERVICE
Story aired in cities nationwide
Lisa Summers

AMERICAN MEDICAL NEWS
Anne Leavitt & Dana Beyer

BOOK ON MISCARRIAGE
by Jon Cohen to be published by Houghton Mifflin
Gertrude Merzbach

OUR MEMBERS from page 7...

DES Action does not recommend. Those who know of their exposure and read about it in the paper, or see it on TV, are reminded they must be advocates for their own health. It's so easy to let things slip even though we know we should make our annual doctor's appointments.

Then there are those who were exposed and don't know. If only one such person heard about DES last year and checked into it, then we could call our efforts a success. But anecdotal evidence tells us there must have been quite a few because each time a story ran, the CDC recorded a steep upsurge in the number of visitors to its DES Update website!

But we aren't just trying to reach the DES exposed community, important as that may be. Our

health care providers watch TV too! Perhaps they won't readily brush off a DES daughter's concerns after they've been aired recently in the media.

Besides, insurance company executives are swayed by news coverage, as are lawmakers who fund vital research. In the court of public opinion it helps to have decision makers know something of who we are and what we want.

Having spoken with so many DES Action members this past year, I'm pleased to report we are a knowledgeable bunch. You must all be reading the *Voice* because – to a person – you understand the importance of DES exposure in your life. In my search for the right people for interviews in different cities I sometimes contacted non-members. However, the difference was startling and I did that only as

a last resort. I remain amazed at how well informed and helpful our members are!

As evidenced by the accompanying list, it's clear we've made great strides in getting our story covered in the news media. It couldn't have happened without the willingness of DES Action members, whose efforts are very much appreciated. They grasped the importance of what they were asked to do, and rearranged busy schedules to meet with reporters. Our heartfelt thanks go out to you.

Of course we are nowhere near done. We'll continue working with the media in telling the DES story about this so-called "wonder drug," that was prescribed to ensure healthy babies but left a cruel legacy to many families instead. ■

DES Action
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anniversary
1978-2004

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