

30th Anniversary Party Planned for September	3
DES Action Heroes.....	4
Bioidentical Drugs Come Under Scrutiny	7

Most DES Daughters Have Annual Pelvic Screenings — But A Surprisingly Large Number Do Not

“Cervical Screening and General Physical Examination Behaviors of Women Exposed In Utero to Diethylstilbestrol,” Elizabeth A. Camp, et al, *Journal of Lower Genital Tract Disease*, Volume 12, Number 2, 2008.

Reviewed by Kari Christianson

Do DES Daughters have more Pap smears and gynecological exams than unexposed women? Are DES Daughters following gynecological screening recommendations? Do DES Daughters go to the doctor for general health screening more often?

To answer these questions Elizabeth Camp, MSPH, from the School of Public Health, University of Texas Health Science Center, and her colleagues with the National Cancer Institute (NCI) DES Follow-up Study analyzed responses of 3,140 DES-exposed women and 826 unexposed

recommendation includes all DES Daughters, whether or not they have experienced structural or tissue changes. Additionally, the screening is to begin at age 14, four years earlier than unexposed women.

So, what are the results of this analysis? Let's start with gynecological visits. “Among women without a reported history of CIN (cervical intraepithelial neoplasms which are abnormal growths of precancerous cervical cells), DES-exposed women were more likely than unexposed women to exceed recommendations for Pap smears, whereas among women with a history of CIN, this was not observed.”

The researchers present the possibil-

ity that women with a history of DES exposure, but who have not had CIN, are aware of their increased risks for abnormal tissue changes, which influences seeking frequent exams. DES Daughters with a history of CIN followed but did not exceed screening recommendations.

Additionally, “among all women, DES exposure was not associated with receiving more general physical visits.” This study found that the history of chronic diseases among DES-exposed and unexposed women was exactly the same at 28%. (Chronic disease includes a diagnosis of diseases such as: lupus, scleroderma, rheumatoid arthritis, mul-

continued on page 3

“I am surprised to learn that so many DES Daughters reported not getting their annual pelvic screenings as they should.”

Pat Cody, Co Founder, DES Action

women from the 1994 questionnaire.

Annual gynecological exams for DES Daughters were recommended by the Department of Health, Education and Welfare in 1978, the NCI in 1980 and the American College of Obstetricians and Gynecologists in 1994. This

The Latest on Hormones and Breast Cancer

By Pat Cody

Connections between hormone use and breast health are newly detailed in three medical journal articles. While most of the study participants in this research, ages 50 – 79, probably were not DES exposed, these reports are important for DES Daughters who already have a greater risk for breast cancer and must be vigilant about scheduling annual mammograms.

“Hormone Replacement Therapy Increases Breast Cancer Recurrence,” L. Holmberg, et al, *Journal of the National Cancer Institute*, March 2008.

“Health Risks and Benefits 3 Years After Stopping Randomized Treatment with Estrogen and Progestin,” G. Heiss, et al, *Journal of the American Medical Association*, March 5, 2008.

“Conjugated Equine Estrogen and Risk of Benign Proliferative Breast Disease,” T. Rohan, et al, *Journal of the National Cancer Institute*, April 2008.

- Lars Holmberg of King's College, London, and his team found that the 221 breast cancer survivors in his study who use HRT have more than double their risk

continued on page 3



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Please make checks payable to **DES Action.**

I am a: ☐ DES Daughter ☐ DES Son ☐ Other ☐ DES Granddaughter or Grandson
☐ DES Mother of a: ☐ Daughter ☐ Son

NAME

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Join OnLine Support Group for DES Daughters

Want to be in touch, via e-mail, with other DES Daughters? As a benefit of being a DES Action member you can join the DES Action Daughters On Line Support Group. That way you can ask questions and share experiences common only to those of us who are DES exposed.

To join the DES Action On Line Support Group simply send a blank e-mail to:

DESactionDaughters-subscribe@yahoogroups.com

You'll receive an e-mail back from Yahoo! Groups confirming your request to join. It offers two registration options and the easiest is Option 2. Click "Reply" so the note is sent back.

Once we've checked to be sure you are a current DES Action member, you'll receive a welcome to the group letter explaining how to send messages. Then you can participate in the e-mail conversations, or just quietly read and enjoy the learning experience.

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MISSION STATEMENT

The mission of DES Action USA is to identify, educate, support and advocate for DES-exposed individuals as well as educate health care professionals.



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Annual Pelvic Screenings *from page 1*

tiple sclerosis, chronic ulcerative colitis, diabetes, thyroiditis, hyperthyroidism, anemia, asthma, and chronic fatigue syndrome.) The mean age of the unexposed women was 42 years; the mean age of the DES-exposed women was 40 years.

Most perplexing is the finding that 29% of DES Daughters were not following the recommendations for screening and had not received annual Pap exams in the past five years. This finding even included DES-exposed women with a history of precancerous cervical cell growth.

"I am surprised to learn that so many DES Daughters reported not getting their annual pelvic screenings as they should. My hope is that in the years since the questionnaire more DES-exposed women have heard the warnings and are taking them seriously," says DES Action Co-Founder Pat Cody. "DES Daughters have a life-long risk for vaginal and cervical cancer so they must be vigilant about being screened for it every year," she adds.

A follow-up analysis using more recent data to compare and contrast results is planned. Researcher Camp joins Cody in hoping the numbers show an increase in the percent of DES Daughters receiving their annual screenings.

Camp acknowledges that access to health care and insurance status may be involved in this noncompliance for recommended gynecological screening. And she recommends that future educational efforts should be directed at encouraging the exposed population to comply with the recommended annual screening exam. One thought she puts forth is the possibility that "periodic reminders from the offices of attending gynecologists may increase the number of annual visits."

As reported frequently in the VOICE, an annual gynecological screening exam is still the standard of care for a DES Daughter. To find a specific description of the DES screening exam and the annual recommendations, please visit our web site at www.desaction.org.

DES VOICE

Celebrate With Us!

Saturday, September 20, 2008 from 7 – 10 pm
New York City Fire Museum (<http://www.nycfiremuseum.org>)

Help DES Action celebrate our 30th Anniversary. Please join us for this fun event in New York City. It will be well worth the trip!

- Taste delicious and plentiful hors d'oeuvres
- Enjoy musical entertainment
- Watch an entertaining look at DES Action's history in a lighthearted, professionally produced performance
- Meet other DES Action members



We wish we could hold similar gatherings all around the country, however we had to select one location. Much early planning for DES Action occurred in New York City, so it seemed an appropriate place to hold our national celebration.

Proceeds from this fundraising event will help support the work of DES Action. We thank attorneys **Aaron Levine, Michael London, Sybil Shainwald**, and **Patricia Stanford Martin** for generously sponsoring our gathering.

Watch the mail soon for your invitation and we look forward to seeing you in September!

DES Action Gets A New Address, Nothing Else Changes

Just to let you know that in August DES Action is moving to Jupiter, Florida. Executive Director Fran Howell's husband took a new job at the CBS-TV affiliate in West Palm Beach, so the office is moving along with her. Our new address is: DES Action, 187 Via Catalunha, Jupiter, FL 33458

Only our address and email address (to be determined) will change, everything else about our organization is staying the same. Perhaps the only difference is that Fran will be able to relax with walks along the ocean beach, something not possible in Ohio!

Latest on Hormones *from page 1*

for a recurrence or a new malignancy.

- A second research report by G. Heiss and colleagues used data from the Women's Health Initiative (WHI) to learn if cancer risks continue after hormone use stops. Their study covered 15,730 women, half of whom had used Prempro (estrogen and progesterone) and half had a placebo. They looked at their health for 2.4 years after stopping the Prempro. While the number of breast cancers was low: 79 in the Prempro group compared with 60 in the placebo group, this still represents a 27%

higher risk for developing breast cancer than the placebo group had. The "benefits" referred to in the title of this article are that higher risks for stroke and heart attack disappeared soon after women stopping taking hormones.

- Finally, the third recent report on breast health, also using data from the WHI, finds that Premarin (estrogen only) treatment after menopause can lead to an increase in benign breast lumps. This means not only extra biopsies, and worries, but perhaps a link to later cancer if the lumps are identified as "benign proliferative breast disease."

DES VOICE

DES ACTION

A hero among heroes in the DES community is **ROBERT N. HOOVER, M.D., SC.D.**, champion



of DES research at the National Cancer Institute (NCI). His official title is Director, Epidemiology and Biostatistics Program, Division of Cancer

Epidemiology and Genetics. However, to the DES community he's best known as the Chair of the NCI DES Follow-up Study since 1992. He has advocated for DES research within the NCI for over 30 years and makes sure consumer advocates are included in the research decision-making processes. In 1999 DES Action recognized him for his "tireless dedication to research benefiting the lives of DES-exposed individuals." This outstanding research leader models the standard for collaboration and communication among clinicians, researchers and those who are DES-exposed.

*Kari Christianson
DES Action Program Director*

As a Senior Scientist of Developmental Endocrinology at the National Institute of Environmental Health Sciences (NIEHS) since 1972, **RETHA NEWBOLD** studies the



effects of environmental estrogens on reproductive tract tissues. Working with mice whose body systems are similar to ours, she confirms in her

laboratory what humans experience as

a result of DES exposure. Her studies also give a glimpse into what issues may be in our future as we age. The focus now is on DES Grandchildren. What Retha sees in exposed mice is being reported in human populations. We haven't kept track of the many times we've called with questions, and her readiness to help us was another reason we gave her our DES Action Distinguished Service Award in 1999. Her current research includes endocrine disruptors, like BPA, which cause reproductive tract changes similar to low dose DES exposure.

*Pat Cody
DES Action Co-Founder*

ARTHUR "CAP" HANEY, M.D.,

has a life-long interest in women's fertility problems and early in his work realized the significance of DES exposure for many of his patients. At present he is Chair of the Ob/Gyn Department



at the University of Chicago Medical School. His practice now centers on reproductive endocrinology and infertility. He was one of the first clinicians to report on abnormalities in the reproductive system of DES Daughters. While highly regarded as a distinguished researcher, he is known to many of us as a kind and caring doctor. He understands the trauma of losing the ability to have a biological child and his compassion makes a terrible situation easier.

*Pat Cody
DES Action Co-Founder*

You may have heard of some of the names that could be new names to you. All are part of DES Action's 30th Anniversary celebration of special people who have made a difference in the DES community.

In this third installment of our four-part series, we feature contributions of eight important individuals in their fields. Their work on behalf of the DES community makes a difference.

Our thumbnail sketches can't possibly do justice to their contributions, but these profiles say "thank you" to these DES Action members.

If her Irish roots and fiery red hair isn't enough indication that she is a



fighter for our cause, then it is clearly her working for justice for those of us so wrongfully affected by DES that makes her an invaluable part of our community.

PATRICIA MARTIN STANFORD became my attorney in 1999 as I sought to fight the drug companies, and she is now my friend. During our relationship, I have seen her aggressively take up our cause in court. DES Mothers, Daughters, Sons, surviving relatives and DES Grandchildren have sought her help and found a tough litigator and sympathetic advocate.

*Jill Vanselous Murphy
DES Action Member*

NON HEROES

These individuals, while others
are worthy of notice. As part of
the celebration we are honoring several
for their difference for those of us in the

Each part series we recognize the
individuals who are outstanding
and of the DES-exposed has made a

possibly tell their full range of
experience as an opportunity for us to
on Heroes.

MICHAEL FREILICK, DES
Action Sons Network, has been the
torchbearer for
health concerns and
research questions
of DES Sons. Since
1985, and serving
on the board of di-
rectors almost con-
tinuously since that



time, Mike strenuously has advocated
for more education and research on
DES Sons. His volunteer outreach
includes those outside the DES com-
munity, as well. In his home state of
New Jersey he speaks at the activities
surrounding the American Cancer
Society's Relay for Life. Addition-
ally, for years he has talked with male
high school students and their parents
about testicular cancer, relating his
own experiences and the need for
practicing testicular self-exam. And,
from me as a DES Sister, I offer a big
"thank you" to Mike for always un-

derstanding when I call him by my
brother's name.

Kari Christianson
DES Daughter and sister of a DES Son

JULIE R. PALMER, SC.D., has
spent her career as an epidemiologist
focused on wom-
en's health issues.
She is a Professor at
Slone Epidemiology
Center in Boston
and a Principal
Investigator from
Boston University



with the NCI DES Follow-up Study.
Her interest in DES research led
her to the finding that DES Daugh-
ters over age 40 are at increased risk
for breast cancer. Recognizing the
importance of alerting those who
should know, she has made herself
available for media interviews and
done what she can to warn DES
Daughters against using extra hor-
mones of any kind. We appreciate her
continued interest in DES and await
results of her next studies.

Fran Howell
DES Action Executive Director

One of the most recognized names
among DES clinicians and researchers



is **RAYMOND H. KAUFMAN, M.D.**
He has spent years
studying the effects
of DES exposure
and was an original
Principal Investiga-
tor in the DESAD
(DES-Adenosis) Project, which pre-
ceded the DES Follow-up Study of the
National Cancer Institute. Now with
the Methodist Hospital Physicians Or-

ganization/Researcher Institute after
almost 50 years at Baylor College of
Medicine, he continues his research
and clinical practice in Houston. In-
ternationally recognized in 1977 for
identifying the T-shaped uterus as
specific to DES exposure, in 2002 he
was the first, along with co-author
Ervin Adam, M.D., to publish a
preliminary study on DES Grand-
daughters. A charming but tough
questioner, it's always refreshing to
hear his take on research studies.

Kari Christianson
DES Action Program Director

KARI CHRISTIANSON
surely represents the "action" in
DES Action.
Twenty-eight
years ago she
co-founded our
Minnesota chapter
and has been a
volunteer, Board
member and now



Program Director in the years since.
She represents DES Action on the
National Cancer Institute's DES
Follow-up Study Steering Com-
mittee, bringing our real life health
issues to the attention of DES
researchers. Kari passionately edu-
cates the DES community, doctors,
and the general public about DES.
You speak to her on our toll free
phone line and know you are get-
ting the best information available,
from someone who really cares.
Kari converses easily with research-
ers and politicians and is a voice for
us all – DES Mothers, Daughters,
Sons and now DES Grandchildren.

Pat Cody
DES Action Co-Founder **DES VOICE**

LETTERS TO THE EDITOR

Being a DES Daughter, I saw a specialist for my high-risk pregnancy. I went weekly and delivered a healthy baby. She is our miracle. A few years later we tried but could not have another child. So we adopted and our family is complete.

Sadly, my wonderful doctor passed away just as I started one of the hardest times of my life, full menopause at 38. I saw many gynecologists hoping to find one to listen and help.

At age 55, I found one! After a hysterectomy, he recommended estrogen, vaginally, for a month, to heal properly. When I stopped, all my health problems started again.

I checked into natural hormones and my doctor agreed to prescribe them, so long as I get the proper tests. I now use natural vaginal estrogen and topical progesterone made by a compounding pharmacy.

Taking estrogen might sound like the dumbest thing for a DES Daughter. Estrogen is estrogen, natural or not. I asked myself, and my husband, if it's worth the risk with breast cancer a concern. It was a difficult decision, but we both answered, yes. It's about quality of life. I feel healthy again and can enjoy our four grandchildren.

I continue with six month vaginal and breast exams, keep checking my estrogen and progesterone levels, and do what's best regarding my basic health. My doctor takes me seriously. I wish they all did.

Susan Wittich, Cincinnati, Ohio

Editor's Notes: Susan gave us her doctor's name and address so it is now part of the DES Action Physician Referral list. If you know a good doctor please tells us who it is so we can add the name to our growing list. Thank you! 1-800-337-9288

Also, Susan describes her decision to use natural hormones. She did so with her eyes open and maintains a strict

monitoring regime. An article on the next page provides more information on using bioidentical hormones.

I want to tell you about my dear friend who just died of breast cancer. She had been administered DES, Estinyl .5 mg tablets daily when she was 10 years old to pre-empt her height. She had many very tall female relatives and her projected height was forecast to be around six feet.

Her family physician reassured her he had the perfect solution. He prescribed DES to her as a preteen for 2 1/2 years. Yes, the goal of being shorter was achieved as she ended up about 5' 8" tall. But, she developed an enormous estrogen positive breast cancer tumor with extensive lymph node involvement at 43 years of age. It was very resistant to treatment and she died in January, leaving behind

a loving husband and two grade school age children.

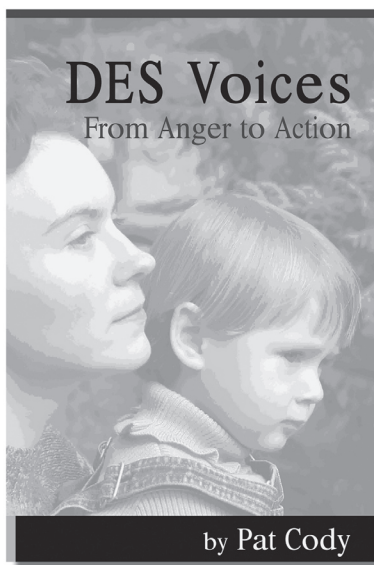
Please warn all your medical professionals of this tragedy. As we learn more about the sensitivity of preteen breast tissue to estrogen, the correlation between my friend's DES prescription and her breast cancer seems to be more than coincidence. Those who were given DES as a pre-teen must be diligent about their breast health through monthly breast exams, annual clinical breast exams, mammograms and perhaps breast MRI.

I submit this to you to help other women who received DES as pre-teens, the so-called Tall Girls, to warn them to be extra diligent about their breast health.

If you use this letter, please do not use my name as I do not want to risk her family finding out about this possible correlation. They would be devastated.

A DES Daughter and Grieving Friend

The DES Story Comes Alive in a New Book



To order a copy of *DES Voices: From Anger to Action* send \$12.95 for each book (which includes shipping) to:

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Don't forget your name, mailing address and contact information in case we have a question about your order.

Natural, Or Bioidentical Hormones, Come Under Scrutiny

By Fran Howell

Earlier this year the Food and Drug Administration (FDA) cracked down on natural hormones – not to stop their manufacture but rather to stop the marketing of them as safe and effective. The FDA believes those claims “are unsupported by medical evidence, and are considered false and misleading.”

So-called bioidentical hormones are derived from plants and are mixed and packaged at a compounding pharmacy, often according to a physician’s specifications for an individual patient. They are similar to, or identical to, hormones produced in the body.

Once health risks to HRT became widely known many women sought relief from menopause symptoms with natural alternatives. DES Daughters, who are rightly skeptical of synthetic estrogens, also became interested.

According to the National Women’s Health Network (NWHN), consumers wrongly assume that natural products are safer than synthetic ones. “Women think because natural hormones are prescribed by a doctor and sold in a pharmacy that they’ve been tested and proven to be safe and effective just like conventional drugs, but that’s not true.”

A 2005 report by the American College of Obstetricians and Gynecologists (ACOG), which is a national medical organization, warned that “most compounded products, including bioidentical hormones, have not undergone rigorous clinical testing for either safety or efficacy.” ACOG also raised concerns “regarding the purity, potency and quality of compounded products.”

An FDA analysis of 29 samples from 12 compounding pharmacies found that 34% failed at least one standard quality test, while 9 of the 10 failing products also contained less of the active ingredient than expected.

By comparison, the FDA reports a test failure rate for FDA-approved drugs is less than two percent.

Joining the chorus of concern is Dr. Susan Love, who authored the highly regarded Dr. Susan Love’s Breast Book. On her Internet blog she writes, “we know that postmenopausal women who have high levels of their own estrogen or testosterone have been found to have higher risks of breast cancer. You cannot get more bioidentical than your own hormones, and, as these studies make clear, even our own hormone levels are not always safe.”

Love goes on to add that, “Women need high levels of hormones to reproduce. These levels then scale down to a safer level with menopause. Artificially maintaining these levels at premenopausal levels is not safe.”

Finally, while Love concedes there is some benefit to mixing a hormone dose to an individual patient, she doubts it can be done all that well because “we do not know what the right levels are for postmenopausal women.”

DES Action cautions against use of all additional hormones — natural or not. Risks, especially for cancer, are thought to be increased for individuals who have already been exposed to excess hormone levels. There are no easy answers when dealing with severe menopause symptoms. If quality of life is diminished enough to warrant an assessment of risks versus benefits, do so in collaboration with your doctor and keep in mind that the lowest possible dose for the shortest time is crucial. But avoid hormone use if at all possible. **DES VOICE**

BOOK Notes

New Menopause Book By An Author We Trust

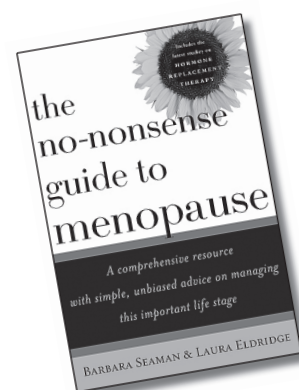
The No Nonsense Guide to Menopause: a comprehensive resource with simple, unbiased advice on managing this important life stage, by Barbara Seaman and Laura Eldridge. Simon and Schuster, 2008, \$26.95.

Reviewed by Pat Cody

Barbara Seaman had a life long advocacy for women’s health concerns, centering her work on the ill effects of hormone use. She wanted to educate us on the over-medicalization of natural experiences, especially menopause. In this, her last book, she wrote about an unintended consequence of studies showing the risks of hormones: doctors’ avoiding hormones and instead prescribing separate medications for each menopausal symptom before adequate research is done on safety and possible interac-

tions. Examples are biophosphates for osteoporosis, statins for heart health, hypnotics for sleep, anti-depressants for hot flashes.

On the positive side, Seaman has much to help us with in her reports on what is good in exercise, stress relief, aging, nutrition, and sleep. We are not going to get younger, but we can go forward with common sense and no nonsense. **DES VOICE**



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Book Launch and 30th Anniversary Reception

What better way to launch Pat Cody's new book, *DES Voices: From Anger to Action*, and begin celebrating DES Action's 30th anniversary than with a party? Hosted on April 26 by Nancy Hersh, Esq., in her San Francisco home, former and current board members and special friends of DES Action gathered to honor Pat and the organization she helped co-found 30 years ago. As part of this celebration, recollections and best wishes from friends, partner organizations and International DES Action affiliates were shared. Here's a sampling of these greetings.

"The work of DES Action shows that a few determined, inspired people can make a GREAT impact."

—Geraldine Oliva, M.D.

"Pat Cody and DES Action have made travel on a difficult road a smoother ride."

—Vickie Dandridge



Pat Cody enjoys flowers sent by European DES Action Affiliates

"Congratulations on 30 years of being there for us all!"

—Joyce Bichler

"Pat is a trailblazer ahead of her time. Thanks for the DES revolution."

—Mary Jean Golomb

"You showed me the way, and then we never gave up moving forward. My heart will go out to you all this fine day."

—Anne Levadou, DES Action France

"DES was a scourge and a rallying cry. Women were harmed, horribly, by DES... and responded by organizing for change. DES Action was born out of anguish and gave birth to hope. DES Action helped so many – with information, a listening ear, and guidelines for high quality health care... Your work is so important. The National Women's Health Network is proud to be your ally."

—Cindy Pearson, National Women's Health Network Executive Director

And finally –

"Breast Cancer Action is delighted to help DES Action celebrate 30 years of kicking butt!"

—Barbara Brenner, Breast Cancer Action Executive Director