DES Action VOICE

Inside

A FOCUS ON DIETHYLSTILBESTROL

SUMMER 2007 #113

Slightly Higher Preeclampsia Risk Shown For DES Daughters

"Preeclampsia Risk in Women Exposed in Utero to Diethylstilbestrol," Rebecca Troisi, et al, *Obstetrics & Gynecology*, Vol. 110, No. 1, July 2007.

Reviewed by Fran Howell

Preeclampsia is a fairly common complication occurring during pregnancy that can harm the health of the mother. It involves a form of high blood pressure and edema (fluid retention) as well as protein in the urine. If seizures develop the more serious condition is called eclampsia.

Using data gathered from the National Cancer Institute DES Follow-up Study, Rebecca Troisi, Sc.D., Dartmouth Medical School, and her team analyzed information on 7,313 live births, comparing numbers between DES Daughters and unexposed women. The result was a small increase in preeclampsia risk for DES Daughters.

She says, "the excess risk with DES was concentrated among women who developed preeclampsia in their first pregnancies, who were (themselves) exposed (in utero) before 15-weeks of gestation and who were treated with magnesium sulfate."

The study's findings show more DES Daughters than unexposed women were treated with magnesium sulfate rather than with other options such as bed rest, diet or more frequent prenatal check-ups. "This greater risk might indicate that DES is associated with more severe preeclampsia," Troisi says, while acknowledging that more research on this is needed.

She also notes that the preeclampsia risk was elevated for pregnant DES Daughters with established uterine abnormalities. Earlier studies have shown that DES can affect the developmental structure of the uterine wall, which may impede the placenta from properly attaching itself. "These observations imply that stromal (uterine wall cell) abnormalities may influence placentation (attachment of the fetus to the uterus) and development of preeclampsia," says Troisi.

Another area of interest for researchers is whether in utero DES exposure affects the way genes work. It is suspected the genes themselves are not faulty but rather the signaling mechanism that turns them on and off may have been altered by exposure. More studies are needed to see if DES-caused alterations in the functioning of genes adversely effects the placenta's implantation. This could potentially explain the elevated risk in DES Daughters for preeclampsia.

It is extremely important for DES Daughters to seek high-risk obstetric care when pregnant, even if they've had a previous successful birth.

It is extremely important for DES Daughters to seek high-risk obstetric care when pregnant, even if they've had a previous successful birth. Careful monitoring, beginning at the earliest stage, must be done to watch for an ectopic pregnancy, miscarriage, preterm labor and now preeclampsia. DES VOICE

Mammograms vs MRIs: *What Is Best For DES Daughters?*

The American Cancer Society (ACS) now recommends annual MRI breast exams, in addition to mammograms, for women at high-risk for breast cancer. Many DES Mothers and Daughters, who know they are at increased risk, wonder what they should do. Respected women's health care provider, **Candy Tedeschi, NP**, graciously answered questions posed on our *DES Daughter OnLine Support Group* listserv. Tedeschi is a member of the DES Action Board of Directors and is well-known for her more than two decades of work with DES-exposed individuals.

Why are MRIs being recommended for some women?

Annual screening mammograms, starting at age 40, along with monthly self-breast examinations, have been successfully used for many years. Since 1991 MRIs have

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DES Action

DES Action USA
158 South Stanwood Rd.
Columbus, OH 43209

desaction@columbus.rr.com
www.desaction.org

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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.

DES Action Contacts

United States

DES Action USA National Office
158 South Stanwood Road
Columbus, OH 43209
desaction@columbus.rr.com
www.desaction.org
800-337-9288

DES Action Sons Network
104 Sleepy Hollow Place
Cherry Hill, NJ 08003
msfreilick@hotmail.com

DES Action Generations Network
desactiongen@optonline.net

DES Action Massachusetts
14 Canterbury Dr.
Canton, MA 02021
aeq5ct@verizon.net

DES Action Pennsylvania
Box 398
Nescopeck, PA 18635
www.desactionpa.org

DES Action Los Angeles
6324 Ivarene Ave.
Hollywood, CA 90068
Pinkkaire@aol.com

DES Action International

Australia
DES Action Australia, Inc.
PO Box 282
Camberwell 3124 Vic. Australia
info@desaction.org.au
www.desaction.org.au

DES Action Australia - NSW
14 Edmundson Close
Thornleigh NSW
2120 Australia
C_devine@bigpond.net.au

DES Action Canada
5890 Monkland Avenue
Suite 15
Montreal, QC H4A 1G2
(514) 482-3204
1-800-482-1-DES
desact@web.net
www.web.net/~desact

England
DES Action UK
Box 128, Blaydon LDO, NE40 3YQ
England
info@des-action.org.uk
www.des-action.org.uk

France
Reseau DES France
12 rue Martinon
40000 Mont de Marsan
France
reseaudesfrance@wanadoo.fr

DES Action Ireland
Carmichael House
North Brunswick St.
Dublin 7 Ireland
info@desaction.ie
www.desaction.ie

The Netherlands
DES Centrum
Wilhilminapark 25
3581 NE Utrecht
The Netherlands
des@descentrum.nl
www.descentrum.nl

MISSION STATEMENT

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1- (800) DES-9288 (800) 337-9288
desaction@columbus.rr.com
www.desaction.org

Executive Director
Fran Howell

Program Director
Kari Christianson

VOICE Editor & Research Liaison
Pat Cody

Board of Directors
President: Patti Negri
Vice President: Karen Fernandes
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Treasurer: Stephanie Kanarek
Ann Giblin
Kim Mazeres
Cheryl Roth
Candy Tedeschi

VOICE Design and Layout
Solunar Graphics, Columbus
(614) 488-9962

Printing
CPMM Services Group, Columbus
(614) 447-0165

Contributors
Kari Christianson
Pat Cody
Fran Howell
Candy Tedeschi
Cecelia Volk

DES Son Shares Message

Michael Freilick, 53, of Cherry Hill, NJ, is a health educator by choice. As a DES Son who had surgery for testicular cancer when he was 29, he learned that men, and especially young men, need to pay more attention to their health. He wants to alert them, and this year has done so in two events.

First was Relay for Life in early June, sponsored by the American Cancer Society of South Jersey. Michael, who has been a member of the DES Action Board of Directors, spoke at this Relay. He also visited Cherry Hill High School East to talk to students there about testicular cancer (which is possibly, but not conclusively linked to DES exposure). It is regarded by specialists as a "young man's disease" since most cases are found in men under the age of 30. High school students are not used to thinking about possible health problems, so Michael uses his experiences and tells how a simple testicular self-exam should be a part of their regular health care. He emphasizes early detection in the message he gives to every audience he reaches, including parents of young men—an important contribution to public health.

Michael Freilick with wife Carol and daughter Michelle

DES VOICE

Know A Good Doctor?

Do you have a doctor you like — who doesn't dismiss your DES exposure as not important anymore? Please let us know because we need names for our Physician Referral List.

Having a doctor you trust is important, and good ones are not easy to find. Share the name and help other DES-exposed individuals locate good health care. We all know how vital that is.

Call our **toll free number: (800) 337-9288**, or email: **desaction@columbus.rr.com** with your doctor's name, address, phone number and specialty. We'll add the name to our list and you'll know you've helped someone else. Thank you!

Honors for a DES Attorney

Sybil Shainwald

Sybil Shainwald is the recipient of the 2007 New York Law School President's Medal, which is awarded to the institution's most outstanding and accomplished alumni. It recognizes her passionate advocacy for safe and effective healthcare for women.

Shainwald took on cases other lawyers deemed impossible to win, including some of the first DES cases. Through the years she proved many times over that DES-exposed individuals were harmed by the pharmaceutical industry's failure to properly test DES and its continued promotion of the drug, even after it was known to be potentially dangerous and certainly ineffective.

She represented 2,000 women in the Dalkon Shield case, traveled to Kenya, Costa Rica and Bangladesh to warn women about toxic chemicals in women's health products, chaired the National Women's Health Network and co-founded Health Action International.

Shainwald graduated from New York Law School in 1976 and her accomplishments are all the more impressive because she attended classes at night, after raising her children and then deciding to become a lawyer. She is in active practice and is listed on the DES Action Attorney Referral list. It can be found on our web site at www.desaction.org or you can request it by e-mailing desaction@columbus.rr.com or calling (800) 337-9288.

DES VOICE

YOUR VOICE

The following article, by DES Action member Cecelia Volk, is another in a recurring series of personal stories to be published in the VOICE. We hope you will enjoy reading about the spirit of our members who are living good lives in spite of, and with, DES exposure. Do you have a DES story that communicates hope? Please e-mail Board Member Ann Giblin, Ann@WinterlakeAssoc.com, for more information.

DES: A Career-Altering Drug

By Cecelia Volk, Esq.
Born: Peoria, Illinois

I was in my early twenties working as a Medical Technologist in the Nuclear Medicine Department at a community hospital in Champaign, Illinois in the mid-70s.

I knew my Mom had miscarried her first pregnancy two years before I was born and that she had said her obstetrician had given her medicine to "strengthen her uterus" before she became pregnant with me. She was also put on bed rest after her first trimester.

But when I went for my annual check-up with a local ob/gyn in Champaign, I was totally shocked when he said "This looks like a typical DES-exposed cervix" and "you will need a colposcopy." I raced back to my hospital ER, which was across the street, to ask a nurse friend what that procedure entailed, as there sure was no Internet to surf in those days. That exam showed typical changes of adenosis and a cockscomb cervix, thus pretty much confirming the "uterus strengthening" medicine was indeed diethylstilbestrol. A review of my Mom's medical records shows she took it *while* pregnant with me, not before.

There was very little information available at the time and I turned to DES Action, still in its infancy, for help to understand what it all meant; and how DES was going to affect the rest of my life. Thus began my life-changing involvement with, and love of advocacy, inspired by those at DES Action who had already advocated on my behalf, and those who still do.

> "I know I have been put on this path only through my involvement and deep respect for the very brave, "Founding" mothers of DES Action."

I moved to New York in the early 80's to attend Sarah Lawrence College for my MA in Health Advocacy because of my working with DES Action. I was in the 2nd class and the program was still forming its mission. The basic idea at that time was to train students to become Patient Representatives or Patient Advocates in a hospital setting. My class, however, was more interested in "community" advocacy.

After receiving my degree, I worked for the New York City Department of Health as a Public Health Advisor in an inner-city junior high school in Brooklyn. The next year I was assigned to another DOH program located at Kings County Hospital and Coney Island Hospital enrolling "high risk" newborns in the department's Infant Health Assessment Program.

Shortly after arriving in New York City, I became very active in DES Action. I also participated in the New York Public Interest Group's (NYPIRG) "Toxic Victims Access to Justice Campaign" to change New York's archaic toxic tort laws. That experience sparked my interest in the law, and in 1987 I was accepted into the City University of New York (CUNY) Law School at Queens College. This school is dedicated to producing "public interest" lawyers and was just perfect for me.

After graduating in 1990, I thought that I would work in the field of Health Law, but fate led me to the Eastern District of New York Federal Court, located in Brooklyn. I was a Pro Se Staff Attorney for almost 11 years; providing Pro Se litigants (those who represent themselves) with procedural information on how to navigate the Federal court system. During this time, I was quite active with DES Action, even serving as a Board Member for a

term. It was the most rewarding volunteering I had ever done, and still have some very close friendships because of that work.

In October of 2001, I became an Immigration Staff Attorney at Gay Men's Health Crisis, Inc. in New York City. All their clients are HIV+ or are persons living with AIDS. As I too have a chronic health condition, I had great empathy for my clients and always gave 100% of my efforts toward securing for them as many benefits as were allowed.

After five years at GMHC, I changed jobs in early January 2007 and am now a Staff Attorney for the LegalHealth Unit at the New York Legal Assistance Group (NYLAG) in Manhattan. NYLAG is a non-profit law firm and all our clients are indigent. Services that NYLAG provides are free. The LegalHealth Unit assists low-income, ill (chronic or acute) clients with securing government benefits; health care proxies/advanced directives/wills; immigration; insurance disputes; special education; credit issues and negotiating workplace accommodations. I conduct off-site patient intake at two clinics of Maimonides Medical Center in Brooklyn as well as at the Community Health Center of Richmond in Staten Island every week.

So finally, I really am practicing *health* law. I know I have been put on this path only through my involvement and deep respect for the very brave, "founding" mothers of DES Action (THANK YOU Pat, Fay, Libby, etc.). My life has meaning and fulfillment; knowing that I am able to help the many patients who are unable to help themselves. I will always honor DES Action for being the guiding force in my life and helping me achieve my goals. DES VOICE

LETTERS TO THE EDITOR

Dear Editor,

It was interesting to read the articles about research involving DES and weight in the last Voice issue. I am mildly Hashimoto's thyroiditis and was unable to tolerate any medications. After menopause I began to slowly put on weight. Whenever I tried to diet nothing really happened — a problem I never had in my more youthful days.

I will be interested in future research findings. When strange things happen to me physically, I often wonder how much the DES made a difference. My mother took it from the 3rd month to the l0th month and stopped only at delivery. That was plenty of time to affect a lot of fetal development.

Denise Wittlin

Editors Note: As you mentioned, dose and timing of exposure do matter but they don't happen in a vacuum. Genetics, exposures to other possible endocrine disruptors and normal body system changes as we age must all be factored in. We join you in awaiting new research results, which will be published in the Voice when they are available.

Dear Editor:

I had to respond to the article in the Spring 2007 DES Action Voice which reviewed "Screening Mammography in Women 40-49 Years of Age.…" As a 52-year old DES Daughter whose cancer was found via routine mammography when I was 44, I would like to let you know that I disagree 100% with the American College of Physicians who "believe that the risks: false positives, unnecessary biopsies, exposure to radiation — outweigh the benefits, since very few women in that age range have risks for breast cancer." I can also tell you that at least half of my "After Breast Cancer" group gasped when they heard the news that mammography was not all that necessary for women aged 40-49, as they, too, did NOT find any lumps during routine doctor's exams and/or monthly breast self-exams. I can only give specifics for my case; even after KNOWING there was a 1.4 cm tumor in my breast, not one technician or doctor could feel it.

Science has improved over the years, and I do not believe that simple mammography, or biopsy, is a horribly dangerous procedure, especially compared to the result of a tumor growing undetected.

Clearly any woman who opts to follow the recommendation of the College of Physicians and not get a mammogram before the age of 50 should be sure to vigilantly have doctor's exams & perform self-exams.

Each woman is different, and each of us needs to make this decision based on all personal medical history. But I say that it is wonderful that we are all able to use a variety of exams on a regular basis, and if the worst thing that happens is an unnecessary follow-up test that proves a growth to be non-cancerous, I think we'd all agree that would be better than missing a cancerous tumor.

Barbara Kornfeld

Editor's Note: We couldn't agree more. DES Daughters who are 40 and above need yearly mammograms. We cannot stress that too strongly!

MRIs *from page 1*

become a supplemental tool to mammography and have proved helpful in the diagnosis of breast cancer. MRI, or magnetic resonance imaging, uses a combination of magnetic fields and radio waves to create an image of a body part, in this case of the breast. The ACS recommends that breast MRI be done with a dedicated breast MRI machine and that the MRI center have a physician familiar with reading breast MRIs to increase accuracy. Currently not all centers are fully equipped.

Is DES exposure considered a breast cancer risk factor when discussing possible MRI use?

I have yet to find anywhere that DES exposure was factored in when considering risks. I looked at the assessment tools the National Cancer Institute (NCI) uses, as well as others, and NONE mentioned DES. The NCI uses these factors for assessing breast cancer risk:

- Current age—women over the age of 50 are at greater risk
- Age at first period—women who got their first period before age 12 are at slightly higher risk as they have a longer time of estrogen exposure
- Age at first birth—women who deliver their first live born child over the age of 30 are at greater risk
- Number of first-degree relatives (mother, sister and/or daughters) with breast cancer—one or more increases lifetime risk.
- Number of previous biopsies whether negative or positive—while breast biopsies don't cause cancer, it is felt that whatever prompted the need for biopsies increases risk
- At least one breast biopsy with atypical hyperplasia—increases risk

As for assessing *high-risk*, ACS guidelines also include:

- Inherited BRCA 1 or BRCA 2 gene mutation (breast cancer genes)
- Having a first degree relative (parent, sibling or child) with BRCA 1 & 2 mutation even if they haven't been tested
- History of radiation to the chest between ages 10-30 usually for Hodgkin's disease
- Li-Fraumeni syndrome, Cowden syndrome or Bannayan-Riley-Ruvalcaba syndrome (these are rare diseases)

The ACS feels there is insufficient evidence to recommend for or against MRI screening for women at *moderately high-risk*. That includes those with:

- Lifetime risk of 15-20% according to risk assessment tools based mainly on family history
- Personal history of breast cancer, ductal carcinoma-in-situ (DCIS), lobular carcinoma-in-situ (LCIS), atypical ductal hyperplasia (ALH) or atypical lobular hyperplasia (ALH)
- Extremely dense breasts or unevenly dense breast on mammogram. Breast cancers tend to develop in areas of greatest density.

So I consulted with Long Island breast specialist, Marie Chen, M.D., who told me that determining who is at high-risk is still very complicated. Dr. Chen says doctors must also factor in other considerations when assessing whether risk is moderate or high. They include race, age at menopause, oral contraceptive use, hormone replacement use, obesity, high fat diet, alcohol use, sedentary life style and environmental exposures.

What about DES Mothers who also have a breast cancer risk?

DES Mothers are at increased risk but less so than DES Daughters. Whether they should have annual MRIs will probably depend on each individual mother's risk factors. It is something to discuss with their doctors.

If a DES Daughter has been treated for breast cancer in one breast, should she get annual MRIs to check for cancer in the other breast?

Having breast cancer in one breast increases the risk of breast cancer in the other breast. The absolute risk of developing cancer in your other breast is about 5-10% in the ten years after your cancer diagnosis. In the New York area, insurance companies are paying for MRIs for recent breast cancer as part of cancer staging, for history of breast cancer in one breast and for lobular carcinoma-in-situ. But coverage varies by state.

What are the advantages of having an MRI?

Advantages of MRI:

1. Sensitive to small abnormalities. More likely to detect cancer than mammography, but not perfect
2. Effective with dense breasts
3. Can locate primary tumor in women whose cancer has spread to armpit lymph nodes or chest wall
4. Can help choose treatment modality, e.g. lumpectomy vs. mastectomy
5. Increase detection of recurrences
6. Can detect multifocal disease better
7. Good for evaluating women with breast implants

Drawbacks to MRI:

1. Can't detect microcalifications (microcalifications often associated with early stage cancers such as DCIS). Mammograms do pick up microcalifications
2. MRIs are more sensitive but less specific—i.e., can miss cancers that mammograms detect
3. Moderate false positive rate since can't tell difference between benign and cancerous masses. Increases anxiety due to increased need for biopsies and need for more biopsies
4. Cost—expensive
5. Need dedicated MRI breast machine with skilled physicians to read films

MRIs are used with a Gadolinium injection through an IV line. The injection makes images stand out with greater contrast. There is a slight chance of allergic reaction.

The procedure takes 2-6 film sequences with each lasting 2-15 minutes for a total length of 30-60 minutes, which can cause claustrophobia.

MRIs are more sensitive than mammography in some ways. For instance MRIs are good for women with breast augmentation, help with staging breast cancer and help in determining appropriate treatment and follow-up after diagnosis. Dr. Chen tells me that MRIs miss cancers mammograms find, and mammograms miss cancers MRIs find. Neither is perfect.

My concern is having had a total hysterectomy in my late thirties I was put on HRT. Should I have an MRI?

DES exposure and hormone replacement therapy use will probably not qualify you for MRIs if they are your only risk factors. HRT is not one of the major factors that risk models take into consideration. It is best to talk with your doctor about this.

Any thoughts as to whether insurance companies will cover MRIs?

This is probably the hardest question to answer. Insurance companies have their own rules on covering MRIs, and how often. Cost varies from $1,000-$3,000 depending on location in the country. Insurance companies may cover one woman but not another and rules on MRI approval vary from one insurance company to another.

Conclusion:

DES exposure is only one risk factor for breast cancer. Each DES Daughter and Mother must discuss with her health care provider ALL of her potential risk factors. Mammography remains the gold standard for breast screening but MRIs definitely have a place. DES Daughters have many problems due to their exposure and many physicians of all specialties are unaware of potential problems. To make radiologists more aware of DES and the increased risk of breast cancer, be sure your referring health care provider writes on the referral that you are DES-exposed and/or you write it on the forms at the radiology facility. Hopefully, making your physician and radiology facility aware of your increased risk of breast cancer will help put DES exposure front and center. But no matter what, be vigilant in getting your annual mammograms, clinical breast exams and doing breast self-exams, whether you have an MRI or not. DES VOICE

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It is true, pennies can add up. Many of our members now use **GoodSearch** to find things on the internet and each time they do, DES Action gets a penny.

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Thank You!

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U.S. Postage
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Columbus, OH
Permit No. 2609

National Office
158 South Stanwood Road
Columbus, OH 43209

www.desaction.org

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Moving? Please let us know...

New Web Site Focuses on Women's Health and the Environment

By Kari Christianson

Where can you find the recipe for an environmentally safe household cleaner? How about ideas for making your community a healthier place to live?

A new web site is worth visiting if you want to make your home and neighborhood more environmentally friendly.

Launched by the Women's Health and the Environment working group of the Collaborative on Health and the Environment (CHE) and the Women's Health and the Environment Initiative to commemorate Rachel Carson's 100th birthday, the web site is full of interesting suggestions.

Of special note is a downloadable Toolkit "which provides everyday actions you can take around the home to reduce exposure to environmental contaminants." It also has "resources to get involved in the larger movement to hold government and industry accountable for protecting us from contaminants."

The Toolkit has three parts. The "What We Know" section cites scientific evidence linking health and the environment. A "What You Can Do" section suggests everyday actions you can take to protect yourself and your family when dealing with such things as cleaning products, food, plastics and cosmetics. And, finally, to fulfill the rabble rousers' longing, there's a "What We Can Do" section which suggests community efforts to protect our health.

The DES Action web site (www.desaction.org) has a link to Women's Health and the Environment or you can go directly to http://www.womenshealthandenvironment.org. There's even an e-mail sign-up to receive news and updates. What better way for the DES-concerned community to address health and environmental issues than through information and advocacy! DES VOICE