

What DES Daughters Need to Know About the New Cervical Cancer Vaccine



by Fran Howell

As a DES Daughter my heart raced upon hearing that researchers are getting close to creating a new cervical cancer vaccine. It's been all over the news recently. Wouldn't it be a relief to just get a vaccination and not have to worry about the cervical cancer linked to DES exposure?

Alas, it is not to be. Gardasil is designed to immunize against the human papilloma virus, or HPV, which is the primary cause of cervical cancer. But it is not the cause of clear cell adenocarcinoma, which is the cancer associated with DES.

Still, DES Daughters should pay attention as this new vaccine is rolled out because research studies show a connection between DES exposure and a greater risk for HPV — the virus the vaccine is designed to protect against.

One possible reason, according to researchers, is that exposure may have altered the immune system in DES Daughters, leading to a lowered ability to fight off a genital infection such as HPV (*E.E. Hatch et al, "Incidence of squamous neoplasia of the cervix and vagina in women exposed prenatally to diethylstilbestrol," Cancer Causes and Control, November 2001*).

The researchers also note that many DES Daughters have a wider cervical transformation zone than non-exposed women. Since that's where many of the pre-cancerous lesions develop, researchers speculate

that the larger area in DES Daughters makes them more susceptible to HPV.

So, while the proposed vaccine will not work against the DES linked clear cell cancer, DES Daughters seem to be at higher risk for the virus the vaccine is designed to prevent.

Merck developed the vaccine and hopes for speedy FDA approval so it can begin marketing the drug in 2006. Another cervical cancer vaccine is set for human trials next year. GlaxoSmithKline Biologicals has its

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New DES Research On Cancer Risks

Interaction between genetic susceptibility and early-life environmental exposure determines tumor-suppressor-gene penetrance," by Cheryl Lyn Walker, et al, Proceedings of the National Academy of Sciences of the United States (2005).

Reviewed by Fran Howell

Scientists may be getting closer to understanding why some people develop cancer and most others do not. It's a particularly vexing question for the DES community. Some DES Daughters develop a cancer linked to exposure (clear cell adenocarcinoma of the vagina and cervix), but others don't. While a mystery for so long, new research may provide a clue.

A two-year study, funded by the National Institute of Environmental Health Sciences (NIEHS), shows that early life exposure to harmful chemicals and drugs during critical developmental periods may actually "reprogram" the way certain genes

respond to estrogen.

This discovery, by scientists at the University of Texas M.D. Anderson Cancer Center, is important because it changes the way we think about cancer risks. It shows that genetic predisposition for disease, along with environmental factors, interact together to increase risks. Researchers have long believed that environmental toxins damaged genes, but these new results indicate that genes may not be damaged, per se, but rather altered, or reprogrammed, to function differently.

Lead researcher Cheryl Walker and her team used rats bred to have a genetic defect similar to one found in some women who develop uterine leiomyomas, or benign fibroid tumors. Some of the rats were given DES during the time of uterine development.

When the DES exposed group reached adulthood nearly all (almost 95%) had developed tumors, which

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Join On Line Support Groups for DES Daughters or Sons

Want to be in touch, via e-mail, with other DES exposed individuals? As a benefit of being a DES Action member you can join either the DES Action Daughters On Line Support Group, or the one for Sons. 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

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

DESactionSons-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.

MISSION STATEMENT

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

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Cervical Cancer Vaccine *from page 1*

own version, called Cervarix, which it wants to begin marketing in 2007.

You can't find a group more aware of the dangers of pharmaceuticals than the DES exposed community. We know better than most that drugs can be hazardous to our health. So I'm certain most of us will move cautiously as these new vaccines get plenty of attention. And they should, because cervical cancer is the second most common cancer in women worldwide, after breast cancer. In de-

veloping countries it is the leading cause of cancer deaths for women. In the U.S., death rates are low because of widespread Pap screening.

And that could actually be problematic for DES Daughters in a few years. Should this new cervical cancer vaccine live up to expectations and significantly reduce the incidence of cervical cancers, it's likely the need for annual pap smears will decrease. It's entirely possible that insurance companies won't look kindly on continuing to cover them as the number of

HPV caused cervical cancers declines. While a wonderful thing for most women, it could mean that as DES Daughters we may have a harder time getting the annual screenings we need.

There is a lifelong risk for clear cell adenocarcinoma of the cervix and vagina if you were exposed to DES before birth. So while this vaccine is designed to protect against HPV caused cervical cancer, DES Daughters will still need their annual gynecological exams and should never be deterred from getting them.

Research On Cancer Risks *from page 1*

were larger and more numerous than those in the set of rats that was genetically predisposed but did not receive DES. (Their tumor rate was about 65%). Those who did not have the genetic defect but were given DES did not develop tumors.

"This study is telling us that an environmental reprogramming of a normal response, combined with an inherited gene defect, work together to promote cancer," said NIEHS Director David Schwartz, M.D. "If this model is correct, it will help doctors determine which individuals are more likely to develop cancers of the uterus, breast and prostate."

According to Walker, "Most people with a family history for a particular disease are concerned about their recent exposures to harmful agents in the environment. We are just beginning to realize that exposures received decades earlier, during critical developmental stages, may be much more important in determining who develops cancer as an adult."

She goes on to note the reason the DES exposed rats had more, and larger, tumors is because of DES' ability to influence estrogen, a hormone that regulates the activity of key genes involved in cell growth. "We found

that the DES treatment somehow 're-programmed' how these genes respond to estrogen, making them much more responsive to estrogen than normal. We realized that the DES exposure enabled estrogen to drive the tumor development when combined with a genetic predisposition."

"These data suggest that environmental exposures during development of the uterus can interact with a pre-existing genetic susceptibility to increase the risk of disease," said Walker. "We are looking at a new kind of gene/environment interaction that determines who gets cancer and who doesn't."

As for DES exposure in humans, Walker notes that while it can lead to vaginal and cervical cancers, most DES exposed women do not develop them. She says it suggests that genetic predisposition is an important part of the equation when environmental factors (such as chemicals and drugs) are introduced.

As tests are developed for determining a person's predisposition for cancer, Walker says more studies will also be done into how environmental toxins reprogram genes. "NIEHS is partnering with the National Academy of Sciences to fund additional research on early-life exposures and cancer risk in human populations," she says.

Researchers have long believed environmental toxins damaged genes, but these new results indicate that genes may not be damaged, but rather altered, or reprogrammed, to function differently.

New NIEHS Director Tuned in to DES Research

The newly appointed director of the National Institute of Environmental Health Sciences (NIEHS) is David A. Schwartz, M.D.

Since a significant amount of DES research is being done with funding from NIEHS it is important to keep our issues front and center with the new director.

DES Action is a member of the Collaborative on Health and the Environment (CHE). During a conference call for organization members earlier this year, DES Action Program Director Kari Christianson was reassured when she heard Schwartz make it clear that he is aware of the excellent work being done by NIEHS researcher Retha Newbold. Many of her studies involve DES, and in particular, DES Grandchildren.

DES Action has always supported and appreciated NIEHS research on DES and we look forward to the leadership of Dr. Schwartz in research relevant to our issues.

YOUR VOICE

The following article, by DES Action member Sherry Weinman, is the first in a recurring series of personal stories we will be publishing in the VOICE. Intended to be inspiring, 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.

by Sherry A. Weinman

I am a 52-year-old DES daughter. I was raised in the South by loving, progressive, yet traditional parents who nourished me equally on two unambiguous messages: That I was part of a new generation of women who could do anything, become anything we wanted; and, that the path to lasting happiness was in getting married and having children!

I bought into both messages completely — first establishing a heady career in broadcast journalism and television production management and then, at the age of 34, marrying my brilliant husband, an attorney with three fantastic teenaged children from his first marriage. That was 1988.

Given my age and status as a DES daughter with a history of dysplasia, abnormal biopsies, and what had always been described to me as an unusually small cervix, we lost no time in attempting to have a baby together, a path we'd already agreed upon during pre-marital discussion and negotiation. (What else would one ex-

pect from an attorney?)

After trying without success to get pregnant for about 3 months, we decided to jumpstart the process by seeing a fertility specialist right away to help us complete our dream of raising a child, perhaps children, from our union.

At that moment in time, so full of hope and expectation, I never could have predicted that ten years and 3 specialists later —

"It was learning the lesson of 'letting go' of a child that gave me the courage to move on..."

years involving non-stop, emotion-filled rounds of high-tech fertility treatments, reconstructive surgery on my uterus, and even a major Southern California earthquake that damaged much of the in vitro fertility lab at the hospital at which I was imminently scheduled for an implantation procedure, but miraculously,

not our percolating zygote — my lifelong dream to someday have children would end in miscarriage and disappointment.

The advice we received from the fertility specialist who was, by then, the third we'd consulted was that it was pointless and perhaps even risky for me to keep trying to get pregnant.

There is nothing easy about letting go of a dream that is programmed and even biologically wired into one's psyche. "People plan, God laughs," I remember thinking at the time, feeling stung by the harshness of those words and of a fate that seemed so unfair and unforeseeable. Since I was working full time in a high-pressure job, I had little choice but to bury the pain and carry on. Most of the time I was okay, having vowed not to let the disappointment ruin our lives. Occasionally, though, I would feel trapped in self-pity, particularly on occasions when there were lots of children around such as on Halloween when child after adorable child rang our doorbell, wrenching my heart.

It wasn't until a few years

later, following a corporate downsizing at the division of CNN where I was then employed, that I experienced the first significant break from work I'd ever had as an adult and, no surprise, a period of authentic mourning for the child and the dream I had lost.

Copious tears, shed on and off over the space of about a year, eventually helped dissolve the raw anger and pain, lingering doubts about past choices, and my fears about the uncharted future. I made the transition to acceptance and even eagerness for a new life that would not include the seemingly predictable stages of raising a family, but would be open to other paths.

Today, I am happily retired from the creative, but hectic life of deadline TV production. It was learning the lesson of 'letting go' of a child that gave me the courage to move on professionally from a career that had been long and successful, but which had lost some of its appeal over 25 years.

I now pour all my inventiveness into not-for-profit endeavors and into my family. A great deal of my time is taken up with caring for my aging parents and in-laws on one side of the generational bridge and for my stepchildren and their newly burgeoning families on the other.

That's right, I am a new grandmother! The adorable Willa Dora Umansky (age 6 months) and Lena Jane Gutman (age 1 month) have given me official entrée into a wonderful club for men and women who get to lavish love and support on a tiny



Three generations of a happy family. From left, Penni Morganstein holds Willa Dora, Ellen Umansky holds Lena Jane and Sherry Weinman couldn't be prouder!

bundle of oh-so-squeezeable flesh and, yes, then give the baby back to her parents for overnight feeding, changing and comforting.

I am not one of those ambivalent grandparents looking for a name to be called by the grandchildren that won't sound old and grandmotherly. Call me anything... just call me, is my motto! Of course, as a step-grandparent, I sometimes have to stand in line behind Willa and Lena's other giddy grandmas and grandpas, but my stepchildren and son- and daughter-in-law are all wonderful about making me feel included. After 18 years of marriage to their father, my relationship with my stepchildren is mature and secure. They, and now their children, are among the greatest gifts in my life.

Occasionally, I like to close my eyes and imagine traveling the world with my grandchildren when they become young adults. After all, about the time they turn 20, I'll only be in my early 70's, and should have at least a few good years of wanderlust left in me.

I still think about the saying, "People plan, God laughs," but now I no longer hear harshness in the words. Instead, I hear the delight of anticipation and joy as I surrender myself to what lies ahead, safe in the knowledge that I can survive, thrive and even be rewarded by the many twists life takes.

I have learned appreciation for the vulnerability that both grounds and frees me to recognize the enormous blessings I've received. "People plan, God laughs," and I am laughing, too.

DES Action Receives National Recognition

by Kari Christanson

The highly regarded National Women's Health Network (NWHN) turned 30 this year. To celebrate, they chose to honor others — in keeping with the spirit of their founders' vision to be a "network" of individuals concerned about women's health.

The NWHN set about finding 30 women's health activists who had demonstrated a strong commitment to women's health advocacy, who consider themselves part of a larger effort to improve women's health and who have done important work that is an inspiration for others.

"Special thanks were given to those who founded DES Action, and to those who have maintained the focus and integrity of our organization through the years."

DES Action Co-Founder Pat Cody, long-time former Executive Director Nora Cody and the entire DES Action organization are proud to have been recognized as national leaders in the women's health movement.

The NWHN held a celebratory gathering in Washington, D.C. and Lisa Summers represented us. She is a former DES Action board member and is the

director of professional services for the American Council of Nurse Midwives.

She says it was a great feeling to see that, "there are many who recognize the groundbreaking work done by DES Action and they are very appreciative. Our organization has a long and important legacy in the women's health movement and we can all be proud. Special thanks were given to those who founded DES Action, and to those who have maintained the focus and integrity of our organization through the years."

All 30 honorees are featured on the NWHN web site, www.nwhn.org. The description of DES Action reads, in part:

"DES Action was one of the first issue-specific groups that arose from the women's health movement. . . . Because there were several separate pockets of DES activism by mothers and daughters in Boston, Long Island, NY and San Francisco, DES Action really defines the grassroots organizing of the 1970s. It coalesced in San Francisco, where DES Action created educational materials and quickly became active on the policy level, calling for a halt to DES' other uses, including as a morning-after pill or to fatten animals sold for food.

DES Action's work broadened as the full effects of DES emerged and it became clear that mothers, sons, daughters, and even grandchildren are harmed by the drug. DES Action's activists have successfully lobbied Congress to pass

legislation on research and continued educational efforts.

DES Action continues to be a strong voice challenging the pharmaceutical industry's heavy focus on, and marketing of, prevention through pills. . . ."



NWHN Executive Director Cynthia Pearson at the 30 for the 30th celebration honoring DES Action and other activist individuals and groups. (photograph by Peter Cutts)

As stated in their mission, the National Women's Health Network "aspires to a health care system that is guided by social justice and reflects the needs of diverse women." DES Action is thrilled and humbled by the NWHN's recognition of our organization and we are deeply grateful for this honor. We look forward to continuing our partnership as we work together to improve not only women's health, but specifically, the health of all who have been touched by the drug, diethylstilbestrol.

Settlement Hammered Out for Dutch DES Victims

A settlement has been agreed to by Dutch pharmaceutical companies, their insurers, the Dutch DES Fund and the DES Centre. If approved by a judge, it will provide damage settlements for DES-victims in the Netherlands who were exposed to DES before 1977.

The collective settlement has been agreed upon to ensure that Dutch DES-victims receive compensation. It is designed to prevent them from having to file their own legal cases — although they can opt out and pursue litigation if they choose.

This proposed settlement is for DES Mothers, Daughters and Sons. Drug makers and their insurers have placed \$38 million euros (about \$45 million dollars), into the DES Fund in the Netherlands.

While this type of settlement can be put together in Holland, it is unlikely to be tried here in the United States.

No class action suits have been allowed to go forward in this country because of the variety of individual DES dosage exposures and resulting health effects.

Besides, U.S. lawyers say individual suits offer the highest probability for success, along with quicker resolution and in general, larger settlements. Things are different in the Netherlands, which has socialized medicine, a registry of DES-exposed individuals and a different legal system.

CDC Survey Update

We are extremely lucky to have such supportive members! A few weeks ago we mailed out surveys to people chosen at random from our database.

The questionnaires were designed to give the Centers for Disease Control and Prevention (CDC) some insights into how their DES Update effort was viewed by those of us in the DES community. It entailed an information program for the general public and health care providers, as well as the DES Update website: www.cdc.gov/DES.



As an incentive, for each returned survey, DES Action will be given \$25 (up to a maximum \$5,000). At this writing, more than half of those who received the packet took time to fill out the forms and return them. That's considered an *extremely high response rate* — and we are thrilled.

I heard from several of you saying that the reason you were so diligent in returning the surveys was to help DES Action. For that we are very thankful.

Once the information is tabulated we'll share it with you.

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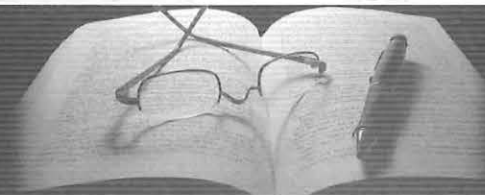
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BOOK *Notes*



by Pat Cody

Our Parents, Ourselves: How American Health Care Imperils Middle Age and Beyond, by Judith Steinberg Turiel. University of California Press, 2005, 306 pages, paper edition \$21.95.

Judy Turiel is a DES Daughter who has used her experiences in two earlier books, *Preventing Preterm Birth* (1988) and *Beyond Second Opinion: Making Decisions about Fertility Treatment* (1998). Now she weaves her own circumstance as a daughter with aging parents into a survey of the shortcomings in elder care.

She starts with Aging in-Place or Elsewhere and Patterns of Decline, and goes on to discuss The Pharmaceutical Age, Health-Care Rationing, End of Life, and A Look Ahead: Baby Boomers Take Stock.

Baby boomers are defined as those born between 1946 and 1964. This is a time span covering many of the readers of the VOICE, who will appreciate Judy's candid and thorough appraisal. It is best read now when sensible decisions can be made before immediate need arises.

