

# DES Action USA Heads Into Its 35th Year of Action!

## Reflections From A DES Daughter Who Had A Place At The Table From The Start

By Martha Cody



When I think of DES Action USA, the first thing that comes to mind is family. My mother was Pat Cody, one of DES Action's founding members. Typically for Mom,

when she learned about the potential harms of DES exposure in 1971, the first thing she did was research everything she could find out about it (which wasn't much, at that point). The next thing she thought of was making sure that I got the appropriate medical care, since I was her only DES-exposed child. She didn't tell me about my DES exposure right away—I think from a combination of guilt and protectiveness. Finally when I was 17, Mom told me, in what had to have been one of the hardest conversations of her life.

Not long after that, Mom invited some friends to meet with her at her dining room table to talk about starting a grassroots, consumer organization to advocate for the DES-exposed. This was also vintage Pat Cody; after you've learned about a problem, bring people together to tackle it collectively. From the beginning, DES Action saw its mission as educating the public and the medical community, and advocating for those who had suffered the effects of this drug. The decision to refuse pharmaceutical company fund-

ing meant that the organization might struggle financially, but would always maintain its integrity and credibility in speaking for the DES exposed.

My own relationship with DES Action has ebbed and flowed over the years. I remember volunteering for a DES-specific pelvic exam at the Berkeley Free Clinic one evening back in the mid-1970's, to educate local medical providers. It is a true test of one's social skills to make small talk with a group of strangers with your feet in the stirrups! Although I supported the DES Action cause, I had mixed feelings about being a part of

the organization. I was forging my own identity, and the combination of my mother's involvement with DES Action and the emotional freight of accepting my DES exposure were too much for me. I admired and appreciated DES Action's work, but wanted to make my own way in the world.

Later, after going through an ectopic pregnancy, endometriosis, infertility, and a hysterectomy at 34, I realized that distancing myself from DES Action was just another form of denial. As with most instances of denial, denial of my DES reality felt good

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## Why DES Studies Don't All Return The Same Results

By Kari Christianson

"Diethylstilbestrol exposure: evaluation of the doses received in France," Michel Tournaire, et al., *European Journal of Epidemiology*, online publication May 23, 2012.

When talking about DES exposure, does total dose make the poison? Why do European and U.S. studies seemingly differ about breast cancer risk for DES Daughters? Does a *higher* prenatal DES dose increase the risk of breast cancer for DES Daughters? Why do research study results vary among countries?

In a Letter to the Editor of the *European Journal of Epidemiology* French researchers, including Michel Tournaire, offer a brief analysis that may shed light on these questions for future studies.

Two DES breast cancer studies, one from the U.S. and the other from the Netherlands came up with different breast cancer risk results. Work done by American researchers as part of the National Cancer Institute (NCI) DES Follow-up Study found an increased breast cancer risk for DES Daughters over age 40. But the Dutch study did not.

These discordant findings in-

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## 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 Online 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 Online Support Group simply send a blank e-mail to:

[DESActionDaughters-subscribe@yahoogroups.com](mailto: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.

## Have You Considered Planned Giving?

Think about including DES Action USA in your estate planning, trusts and wills. Speak with your estate planning attorney to ensure your wishes are correctly put in place.

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## MISSION STATEMENT

The mission of DES Action USA is to identify, educate, empower and advocate for DES-exposed individuals.

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## DES Action USA 35th Year

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momentarily, but wasn't serving me well. My mom asked me if I would do an interview with my local paper about my DES experience, and once again I had my "feet in the stirrups" to educate the public about DES. During that time period, my sister Nora became DES Action's executive director, making the organization even more of a family cause. We all traveled to Washington DC, along with other DES Action members, to lobby for DES legislation and to make lawmakers aware of consumer concerns.

My mother passed away in Sep-

tember 2010, and not long after that I joined the DES Action Board of Directors. Today, being part of this group is a tangible way to carry on my mom's life work of quiet determination to make a difference in the world. In addition to inheriting the oak dining room table where the organization began, I am honored to carry on her spirit in my work with DES Action USA. **DES VOICE**



Fred, Martha and Pat Cody

## DES Studies Results

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trigued Tournaire, who took a closer look at DES prescribing patterns in France from a study there, to see if it might shed light on what is going on between research results from different countries. What he found is that differences in total DES doses prescribed in European countries compared with in the U.S. does have an impact on research results.

What Tournaire found was that among the women in the French study relatively few (110 out of 234 responses) had medical records giving DES dose information, but among those who did, the median dose was **4050 mg**.

Compare that with what was routinely prescribed in America. According to NCI researchers, the American dose, using the so-called Smith and Smith regiment, was routinely **11,000 mg**.

It's also interesting to note in the NCI study that different regions of the U.S. used DES dose protocols different from the Smith and Smith regiment: Chicago, Boston and California DES Daughter study participants often had a higher total DES exposure than DES Daughters in Wisconsin, Texas and Minnesota. Medical records with DES dosage information is confirmed for the 4653 DES Daughter participants in the U.S. study.

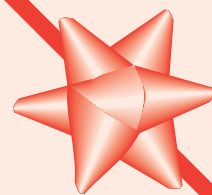
So, what does this mean for re-

search, particularly research about DES Daughters and the link to breast cancer? Be aware of the country from which a study originates and how complete the medical record information about DES dosage is when examining the results.

According to Tournaire's assessment, breast cancer and other adverse

impact risk determinations may have to be made country-by-country depending on prescribing patterns. For example, even though the same drug was used, DES Daughters in the U.S. seem to have a higher breast cancer risk than their counterparts in France or the Netherlands. DES is not a one size fits all issue. **DES VOICE**

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shoes to flowers, clothes, etc., it's there. You'll be surprised at all the choices! Making travel plans? Stop by GoodShop.com first, click on your hotel chain or airline and shop as usual. Those larger purchases generate bigger contributions to DES Action USA.

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Please ask family and friends to GoodShop for us, too. You don't have to be a member to support DES Action USA. Then everyone can feel good about helping our organization!

We thank you!



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# IN OUR OWN WORDS

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## What DES Action USA's 35 Years of Action Means to Our Members

*We have an incredibly loyal membership base, the envy of other organizations. Some of you have been with us for decades. Others have just recently understood the importance of DES in your lives. In anticipation of our anniversary year we asked for your thoughts on what DES Action USA means to you and the responses poured in! One member summed it up in a short sentence: "DES Action brought light where we had none before." We enjoyed reading all the comments and know you will, too.*

Membership by definition suggests community of "like minded" individuals...people with something in common. Whether it's a book club, cultural group (e.g., opera club, theater group), political, religious or any other type of group. DES Action provides this community forum for those exposed to or in some way affected by the drug DES. However, the very nature of our community is different. This isn't a "club" you want to belong to but thank goodness this organization exists. Thank goodness it exists to provide us with the latest studies and research about medical impacts of the drug. Thank goodness it exists to provide information and other resources and support to those who need it. And thank goodness it exists so that none of us ever needs to feel like we're going through this alone.

—Ellice

Our mother, Margaret, had eight pregnancies, resulting in three miscarriages and five live births. Mom was prescribed DES for her seventh pregnancy, which resulted in my birth in 1955. Since that worked "so well," she got more DES when pregnant with the baby who became Joyce. Our mother never felt any sense of anguish over taking DES, as she understood she was just trying to do the best for her children. We were very lucky she felt that way, as we knew of DES Daughters whose mothers felt tremendous guilt. Mom died of a stroke in February 2008 at age 87.

In July 1979, Joyce discovered she

had clear cell adenocarcinoma only a year after her wedding, enduring a long hospitalization and recovery. In May 1980, Joyce's adopted daughter was born and a sad house turned into a happy home. But nine years later Joyce kept having problems thought to be related to her colon, or even "all in her head." It turned out her cancer had returned. Despite a valiant two-year effort, she died in August 1991, missing her 35th birthday by 3 months. A DES friend, Darci Picoult, wrote the play, "My Virginia," loosely based on what happened to Joyce.

Through the years we've all been DES Action members, attending conferences and thirsty for DES knowledge. I read the VOICE cover to cover. Given the devastation DES caused in my family, I know this is no time to let my guard down.

—Mary

In a word: camaraderie. Until I found DES Action USA and ultimately connected with other DES-exposed people, I felt like I was the only one out there, drifting, seeking answers and trying to understand how this happened to only me. DES Action has been and continues to be the only group that has built, educated and advocated for the community where we can share, learn and sometimes just vent about our plight of DES exposure. Because of DES Action, I know I am not alone and have the support of the organization and other exposed individuals. I have made lifelong friends

due to the greed of the pharmaceutical companies!

—Jill

As a member, I can always be assured of up to date, unbiased reporting on the latest information regarding the effects of DES. There are so many "sisters" I have gained, who have suffered the same indignities and health issues—the risk of cancer due to my exposure in utero, the high risk of getting breast cancer, the heart-wrenching difficulty of dealing with infertility, and an affect on my endocrine system that makes me at high risk whenever I am under stress. I have a way to express myself in a forum so that others can respond. I am a first generation DES Daughter, so I don't know what the future may hold in terms of my health. But I do know that DES Action will be there for me—no matter what!

—Ellen

DES Action in Canada closed several years ago and by becoming a member of DES Action USA, I feel less alone. I'm able to connect with other DES Daughters and get up-to-date information concerning DES. If I weren't a member of DES Action, I would not be privy to the fact that DES Daughters need a yearly mammogram. Up-to-date information concerning DES is not available in Canada.

When I need advice, information, suggestions or a place to vent, I'm able to post my query to a group of

extremely intelligent and experienced women who are members of the DES Action DES Daughter listserv.

I've been receiving the VOICE since the mid 1980's and I look forward to reading it from cover to cover. I don't know what I would do if it disappeared.

It's inconceivable to me as a DES Daughter that there was a time when DES Action didn't exist, and I hope and pray with every fiber of my being that it will always be there for DES Mothers, DES Daughters, and DES Grandchildren.

—Pat

Being a member of DES Action USA means instant access to pertinent information as it becomes available. Sharing posts with fellow DES Sisters on our DES Daughter listserv means I can count on reliable feedback within minutes of posting. Sharing similar symptoms we compare products and remedies. Having a common platform to communicate allows us to air our concerns and questions and in return I have personally been rewarded with honest answers and solutions to benefit my physical and mental well-being.

The support group we have formed is strong and growing every day. I have grown in so many ways being able to share in each other's joys and pains, knowing there are many others like me that understand and have truly 'been there.' For all of that, I am thankful.

—Linda

As a relatively new member, this group has been a lifeline to me...I have lived with DES exposure for 53 years without ever knowing...the information I have learned here has been a god-send...now, as I start this major battle, I am armed with knowledge...thanks to all those who have contributed their efforts, energy, and time to keep knowledge about the DES travesty alive...the drug companies don't want us to remember, some of us won't let them forget....

—Pam

Being a DES Action USA member means not being alone in this. It means access to information I probably wouldn't otherwise get. It means support and encouragement. It means having someone make a beneficial difference in my life and hopefully a valuable difference in someone else's life, too. That's where the DES Daughter Listserv plays such a big part. When we communicate with each other and 'talk' about our DES issues, it turns a bad thing into the ability to help others – a good thing!

—Joanna

I am a relatively new member, and could hardly be more grateful to DES Action USA! I learned about my DES exposure in the early '70s when the news hit headlines when I was only 20. Back then I was simply warned to have annual Pap tests. A year or so later, I moved to the UK, where general practitioners blanked every time I conscientiously asked for DES follow-up. Of course, I never conceived, and coped with what I now realize are probably typical DES-related problems, but no health system acknowledgement. I never even saw a gynecologist until I was diagnosed with Lichen Scleroses a few years ago. Then last year, at 57, I was also finally diagnosed with Systemic Lupus/MCTD since infancy. At that point suddenly the system woke up, responding to a reminder of my DES status by committing to giving me annual colposcopies. Since then, my gyn told me she feels it's very likely that before long, research will prove my autoimmune conditions come from DES.

Last winter, when I searched online and discovered DES Action USA, it seemed to me the very best of all DES support sites. Even though I don't live in the USA I joined and immediately received a package of timely information. As a result, I was well briefed before my first colposcopy and able to discuss my case confidently with my gyn. And I've been able to share more special info about breast cancer with my doctor, who is now as impressed by DES Action USA as I am. I don't

like to even imagine what the past few months would've been like without the support and encouragement of this organization! You've made all the difference to me....thank you DES Action USA: keep up the grrrrreat work!

—Colette

I was 19 when the news broke about DES. The only information our family had was from the newspaper article. I rushed to my college clinic and later to one of the NY state centers where they were specifically checking for effects of DES exposure, and was told I seemed fine. Later confirmed by two more gynecologists. And an excellent group of midwives, after I was married and became pregnant. What a huge relief! Until I unexpectedly went into premature labor. And then my next pregnancy miscarried. And the pregnancy after that was ectopic. I was now 30-years old and finally sent to have a hysterosalpingogram that showed I had a somewhat T-shaped uterus. Why hadn't that test been recommended in the beginning, before I ever became pregnant? Simple bed rest might have prevented my daughter's prematurity and resulting brain damage.

I have deeply appreciated DES Action fighting the cover-up and denial by drug companies that manufactured DES, the denial that delayed help until it was too late for many of us. DES Action has fought to discover what we need to know and worked to get the word out to us, to our doctors, to all those who don't even know they are affected. The meager information contained in one newspaper article has expanded to funded studies, surveys, forums, the CDC, books, plays, articles, interviews, listservs, lawsuits and laws. Thank you, all the members of DES Action, for all you've done for all of us.

—Judy

DES Action has been a powerful tool, both (metaphorically) in my pocket and hanging on the wall for whenever

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er it's needed. It's the organization that makes us visible, that educates us, that backs us up, and that means we don't have to take anything from anyone. DES Action is the ultimate successful skeptic. We found out what was being said wasn't true and that what was being done wasn't right. We stopped the use of DES in pregnancy and have given lots of support to DES-affected people. It's a model for those affected by Vioxx, other drugs, and other harmful agents. DES Action shows how a relatively small number of people can help themselves and inspire others.

—Isabel

I am very grateful to DES Action. Thanks to the information you provided, I insisted on high risk pregnancy care, which detected my incompetent cervix. I got a cerclage and went on partial bed rest, and my pregnancy went full term. DES Action also informed me of the necessity to continue annual gynecological exams past menopause. I live in the Washington, DC, area and have access to excellent doctors, but have found many uninformed about the consequences of DES exposure—in some cases, I have educated them.

And finally, the DES Daughter's listserv is the only group of women who understand the fertility/cancer/sexual issues I am dealing with due to my exposure to DES. Grateful thanks!

—Teresa

DES Action has given me a real and priceless sense of community. Sure, I have neighbors, clubs, work associates and many groups and organizations where I have a sense of community—but DES Action is the only place where I can share this health, emotional, embarrassing, scary, personal, life affecting, empowering, horrid, enlightening “DES thing” that NO ONE else understands or knows anything about. I don't want sympathy or understanding from the dachshund club that I couldn't have kids or how I have anxiety attacks each time I go for a gynecology check up. I want community, support, valid information and a place where I can share my “DES life” with like-minded (and like-bodied) people like me. DES Action has given me just that. It really gives me a much-needed sense of community that I can truly get nowhere else. I am eternally grateful and will ALWAYS be a DES Action member and supporter! My life is better because of DES Action.

—Patti

I have been a member of DES Action for over 30 years. Whenever I have had a question, the organization has been there for me. Staff and resources such as the VOICE, and the DES Daughter's listserv have been invaluable resources. Also, seeing what my DES sisters experience, and so beautifully endure, has been a humbling experience. May DES Action continue to thrive—you are awesome. My Deepest Thanks.

—Jane

It's incredibly reassuring to have this organization, which provides information on DES issues of all sorts, and advocacy in many arenas for research and actions that improve our lives and health. And day-to-day, I feel connected to a community of real people who are going through DES-caused medical and emotional issues just like me. I don't feel bewildered, isolated and alone with my own medical problems and questions as I did in earlier years before I had DES Action and its email listserv for DES Daughters. Would that every person with a rare medical condition had a group like this! Thanks to all who work to make it so good.

—Lois

## ***With Thanks to Mary and a Suggestion for All***

We're working at lightening speed in the DES Action USA office thanks to a generous member. When Mary heard our old computer was woefully inadequate for the job and dreadfully slow, she offered to donate a significantly newer version she didn't need anymore.

It sounded too good to be true until a Federal Express delivery made her offer real and changed our lives. No more waiting impatiently for our outdated computer to chunk chunk chunk along at a ridiculously slow

speed. Thank you, Mary!

In-kind donations are a great way to help our small group. As a nonprofit, we can provide you with a tax letter for your donation.

One suggestion—airline reward miles. As a national organization, we have board members living across the country. Flying them to meetings puts a dent in our budget that could be offset with donated miles you can spare.

Please contact us at [info@desaction.org](mailto:info@desaction.org) or 800-337-9288 if you can help. Thank you!



I have been a member of DES Action for more than 30 years. It is hard to put in a few words what this organization has meant to me. I guess I am most grateful that I have had access to clear, straightforward, up to date information every time I was facing another surgery or health challenge. The information has empowered me to be an advocate for myself, sometimes in the face of medical professionals who seemed uninterested or dismissive about my DES exposure.

It has also helped me to know that I am not alone...that there are many, many others who have struggled and coped with the aftermath of DES exposure.

—Carolyn



# In Support of Research Showing DES Daughters Over Age 40 Have Increased Breast Cancer Risk

By Fran Howell

“Breast cancer following diethylstilbestrol exposure in utero: insights from a tragedy,” *European Journal of Epidemiology*, 2012, Volume 27, Number 1, Pages 1-3, Hans-Olov Adami, et al., published online and available at: <http://www.springerlink.com/content/411455urx2618274/>

The August 2006 report from National Cancer Institute (NCI) DES Follow-up Study researchers was chilling. It found DES Daughters over age 40 are nearly two times more likely to develop breast cancer compared with unexposed women. An updated 2011 report confirmed the result. But that wasn't the end of it. A Dutch study failed to replicate the finding.

In a commentary written for the *European Journal of Epidemiology* Harvard Adjunct Professor of Epidemiology Hans-Olov Adami examines both studies and explains why the NCI results are the most dependable.

According to Adami, the NCI researchers have documented dose and timing information regarding prenatal exposure among the DES Daughter cohort in their study. Providing additional confirmation, they also have information regarding vaginal epithelial changes (adenosis, often resulting in profuse vaginal discharge) for each participant. VEC is accepted as a biomarker of high prenatal DES doses. So between medical records and vaginal epithelial changes, DES exposure is unquestionably confirmed in the NCI study.

By comparison, Adami describes what he calls a fundamental limitation of the Dutch study. “DES exposure could be confirmed in only 8% of those included in the ‘exposed’ cohort and existence of vaginal epithelial changes was not assessed.”

So Adami's comparison of the two studies is stark. He calls the NCI DES breast cancer research “high quality convincingly showing a dose-dependent substantial excess risk after the age of forty.” On the other hand, Adami describes the Dutch study as having “methodologic limitations, notably uncertain about actual DES exposure and providing no evidence of an excess

(breast cancer) risk.

He says, “We consider in utero DES exposure and breast cancer risk as one of the rare instances when causality can be inferred with a high degree of confidence based on only one observational study supported by substantial mechanistic data.” Adami adds, “In that context, the sad DES ‘experiment’ is exceptional.”

DES VOICE

## DES Granddaughter and Great-Granddaughter Breast Cancers Seen in Animal Study

By Fran Howell

“High-fat or ethinyl-oestradiol intake during pregnancy increases mammary cancer risk in several generations of offspring,” *Nature Communications*, 11 September 2012, Article: 1053, Hilakivi-Clarke, Leena, Ph.D., et al., <http://www.nature.com/ncomms/journal/v3/n9/full/ncomms2058.html>

Results from new animal research raise the specter of an increased breast cancer risk for DES Granddaughters, on top of the already known increased risk for DES Daughters. This finding about generational effects has not been seen in human studies to date, but DES researchers are on alert for the possibility.

Senior investigator Leena Hilakivi-Clark, Ph.D., professor of oncology, Georgetown University Lombardi Comprehensive Cancer Center, examined breast cancers in the daughters, granddaughters and great-granddaughters of rodents fed a diet supplemented with estrogen.

The researcher team found a 50 percent higher incidence of breast tumors in the exposed rats' progeny

going into the great-granddaughter generation, compared with the unexposed control group. Of note is the increased breast cancer risk through generations was transmitted only through the DES Daughter lineage into the DES Granddaughters and Great-Granddaughters.

Also identified were epigenetic changes in the mammary glands of all three generations of rats following higher estrogen given to the DES Mother.

According to the study's lead investigator, Sonia de Assis, Ph.D., a postdoctoral researcher in Hilakivi-Clark's laboratory, estrogen exposure during the fetal period could disrupt normal epigenetic development, “and affect how genes are turned on or off. These alterations then can be passed on and affect the risk of disease, in this case, breast cancer, in subsequent generations.”

De Assis adds that mother rodents exposed to excess estrogen produced daughters, granddaughters and great-granddaughters with more than the normal number of terminal end mammary buds. This is important because these buds are primary targets for carcinogens.

DES VOICE

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## MEET THE WOMAN WHO WAS THE FIRST TO CONNECT DES AND CANCER

The diagnosis was brutal. Seventeen-year old Sheila Stone-Brennan had clear cell adenocarcinoma of the vagina. Her doctors were mystified. They hadn't dealt with this cancer before and had no idea why this teenaged girl in Syracuse, NY, developed it.



But that was an easy question for her mother to answer. After two successful pregnancies, Mrs. Penny Stone started spotting while carrying Sheila. So she was prescribed DES in high doses through pills and injections. Mrs. Stone blamed DES for her daughter's cancer right from the start. She had no doubt.

According to Sheila, her mother rarely took drugs, so the memory of all the DES she'd ingested stuck in her mind. But, while treating physician Dr. Sydney Doolittle and gynecologic oncologist Dr. Michael Jordan refused to pay attention, Mrs. Stone refused to let it drop. There were numerous opportunities to mention DES through the gru-

eling chemotherapy, surgery and cobalt radiation treatments that Sheila endured to treat the aggressive cancer. One particular conversation sticks in her mind. Sheila was lying on the couch after a chemo treatment and heard her mother on the phone stridently making the case against DES.

Eventually Mrs. Stone wore down Dr. Jordan, who finally broached the subject of prenatal DES exposure to Dr. Arthur Herbst and Dr. Howard Ulfelder. They were handling a cluster of similar cancer cases in Boston. And the rest is history. A check with the other mothers found the DES connection.

"I happened to be with mom when Dr. Herbst called to acknowledge that thanks to her persistence the DES link had officially been made and she'd been right all along. Mom was teary-eyed when she got off the phone," says Sheila.

"She was tenacious in the face of those who didn't believe. I'm proud of her for fighting so hard when others might have given up. But she knew, she just knew, that the DES she'd been prescribed was the cause of my cancer. Mom would be proud today to know she is recognized as the first person to make that connection!"

**DES VOICE**