DES Action VOICE

Inside

A Focus On Diethylstilbestrol

SPRING 2011 #128

DES Was Linked To Cancer Forty Years Ago

Doctor at the Heart of the Discovery Looks Back

By Fran Howell

Sometimes the confluence of events allows for the possibility of a miracle — but only if individuals recognize the signs and act on them. Such was the case 40 years ago in Boston.

First came the strange occurrence noted by gynecologic oncologists at Massachusetts General Hospital. Seven young girls from around New England were referred there for treatment of a rare vaginal cancer seen before only in much older women. Dr. Arthur Herbst and his colleagues took note and in a 1970 article in the journal, *Cancer*, they wrote about it but could offer no explanation as to what was going on. Then came word of an eighth clear cell adenocarcinoma (CCA) case being treated at another Boston hospital. This was nearly unheard of.

Finally, the mother of one of the girls provided a clue. Her simple question was whether the anti-miscarriage drug she had been prescribed while pregnant could have played a part in her daughter's cancer more than a decade later.

It seemed improbable, but with little else to go on the doctors followed up. To their enormous surprise, medical records confirmed that seven of the eight mothers had something in common – they had been prescribed DES while pregnant! None of the unexposed female children born in the same hospitals at the same time developed vaginal cancer.

Significance of the Finding

Dr. Herbst's April 22, 1971, *New England Journal of Medicine* article about the discovery solved the cancer mystery. DES was associated with these cancers. Prior to this, doctors and researchers had not considered the possibility of adult onset of disease from prenatal exposures. Now, forty years later, it is something we hear of frequently, but at the time this was a revolutionary concept.

The *Journal* has strict rules about

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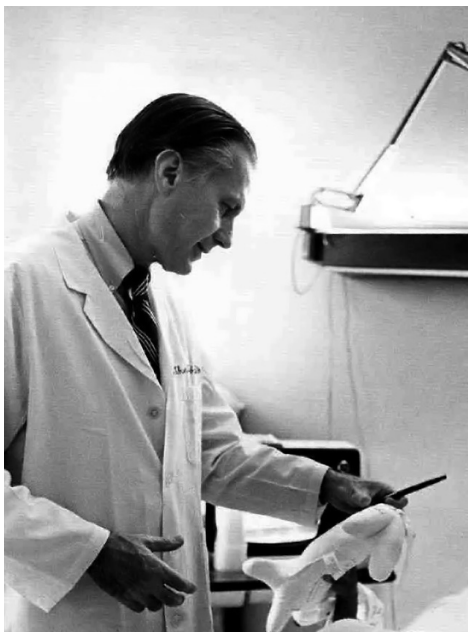

While on hospital rounds, Dr. Herbst signs an autograph dog for a patient.

Important Historical Review of the DES Tragedy

"The Long-Term Effects of In Utero Exposures – The DES Story," *The New England Journal of Medicine*, Annekathryn Goodman, et al., published at NEMJ.org, April 20, 2011.

Reviewed by Kari Christianson

The 40th anniversary of the Herbst article about the association of prenatal exposure to diethylstilbestrol with vaginal cancer was a milestone not just for the DES community, but also for *The New England Journal of Medicine* and the medical community. In this "Perspective" article, the authors offer a compelling synopsis of the still unfolding lessons to be learned from DES and how reproductive tract changes caused by DES have affected women, men and the practice of medicine.

The final four paragraphs of this article speak directly about our experiences as DES-exposed individuals:

"For the women who were exposed to DES in utero, it meant being subjected to the trauma of multiple pelvic examinations with

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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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Dr. Herbst *from page 1*

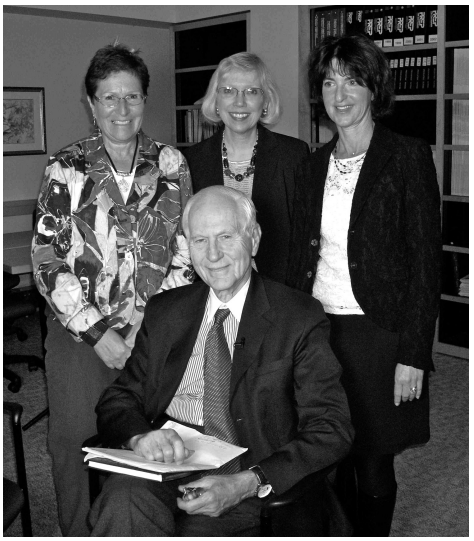
leaking article information until it is published. Dr. Herbst recalls the fright he got shortly before publication, when CBS News correspondent Daniel Schorr called his office. A news story right then about the association between DES and cancer might kill the journal article. With much trepidation Dr. Herbst says he took the call, only to find out that one of the reporter's relatives was in Boston and "wanted me to see her as a patient." It was not a story about DES. But Dr. Herbst knew there would be plenty once the article came out.

He and his wife spent a long weekend in the country before the article was published, and then his life and career changed forever. Dr. Herbst remembers spending significant time with reporters to help them fully understand the findings, so they could write their stories without sensationalizing them. "Information had to get out, but I felt a responsibility to avoid having it cause hysteria," he says.

While Dr. Herbst explained that prenatal DES exposure was associated with cancer, he made it as clear as he could that not every DES Daughter would get vaginal cancer. And most did not. But Dr. Herbst stressed the need for health screenings of DES Daughters. He takes comfort in knowing that the national DES discussion he helped start resulted in the finding of tumors in some young women who otherwise would not have been checked. Many were discovered early enough for successful treatment.

Dr. Herbst is also aware that the DES discovery pushed medical research forward in a new direction. Current studies of prenatal environmental disruptor exposures harken back to what was first learned about DES. What happens in the womb matters.

The fact that a cluster of DES-related cancers all turned up at the same time in Boston in a group of young girls who should not otherwise have been stricken by the disease is, as Dr. Herbst describes it, "very surprising and unusual." He acknowledges that without fate bringing everyone together as it did, the dangers of DES exposure might not have been uncovered in 1971, or potentially, ever. DES VOICE



Marking 40 years since the historic association was made between DES and cancer, Dr. Arthur Herbst reminisces with DES Action's Fran Howell and Kari Christianson along with DES Cancer Network's Susan Helmrich.

Historical Review *from page 1*

colposcopy and repeated biopsies, as well as living with the fear of developing cancer. Small, T-shaped uteri and other uterotubal anomalies that made it impossible to accommodate a growing fetus caused many of these women to have miscarriages — which occurred at twice the rate found among their non-DES-exposed contemporaries. Some sons of women who were given DES have also been reported to have epididymal cysts, microphallus, cyrptorchidism, or testicular hypoplasia. The enormous health care costs for this cohort and the disruptions to their lives cannot be fully measured; in some cases, these effects have been devastating.

"The lessons learned from the DES story are powerful. Endocrine disruptors may cause alterations in the reproductive tract that have severe consequences and form the basis of disease in adults decades later. Endocrine disruptors may come not only from ingested medicines, but potentially also from the environment through food. It is very difficult to recognize a teratogenic consequence of a prenatal exposure when the malformation does not manifest until 20 years later.

"The lessons learned from the DES story are powerful. Endocrine disruptors may cause alterations in the reproductive tract that have severe consequences…"

"There continue to be unanswered questions about the cohort of DES-exposed offspring. Will they encounter other unique health problems as they age? A slight increase in the rate of breast cancer among DES-exposed women over 40 years of age has been reported, but there has been no increase in other gynecologic cancers. Are the children of DES-exposed people at higher risk for genetic changes and disease? Epigenetic changes have been seen in studies in animals. However, a 2008 study of third generation — the grandchildren of women who were given DES during pregnancy — did not uncover an increased risk in humans.

"Ultimately, the DES story humbles us. It serves as a reminder that though the narrow lens of today might reassure us that an intervention is safe, it is only with the wisdom of time that the full consequences of our actions are revealed."

Thanks to The New England Journal of Medicine and these authors for recognizing 40 years of DES research and spotlighting our DES health concerns – past, present and future. DES VOICE

The DES Experience: The First Case of Drug Regulatory Failure

By Barbara Mintzes, Ph.D., Assistant Professor University of British Columbia

This is from a fascinating paper given at the Reseau D.E.S. France Congress on Nov. 19, 2010 in Paris. This is the second in a series of articles we are running in the VOICE that were taken from Mintzes'presentation. Watch for the final segment in the next issue.

DES was first produced and sold long before the era of modern drug regulation, which began in the early 1960's. After the thalidomide disaster, systematic evidence of efficacy and safety began to be required before a drug could be marketed. It would be easy to say that the DES tragedy could not happen today because of much stricter regulations. But is this so?

Much of the experience with DES continues to have resonance today.

1938, the year that Charles Dodds first synthesized DES in the UK, is the same year that the U.S. Food and Drug Administration (FDA) obtained authority, through the Food, Drugs & Cosmetic Act, to require manufacturers to provide evidence of safety in order for medicines to be approved for marketing.

DES was the FDA's "first controversial test case" after the agency had been awarded this new power. A number of pharmaceutical companies applied for approval of DES in 1940. The FDA refused these applications because of evidence of carcinogenicity in animal studies and concern about the potential for harm to humans. The companies were told they could reapply if they were able to gather sufficient evidence of safety in women.

What followed was an intense lobbying effort in which all of the companies involved joined forces to jointly apply for approval, with the company Eli Lilly taking the lead. They used a strategy of involving many physicians in clinical trials in which doctors were provided samples of DES to try on patients. This was the approach used at the time to prove efficacy of new drugs. An interview with an FDA reviewer notes that: "companies routinely sent new remedies to doctors and asked them to try the medicine in patients. Such testing was uncontrolled and entirely anecdotal."

In a compromise with manufacturers that was to prove disastrous in the longer run, the FDA approved DES in 1941, but insisted that it be available only on prescription and contraindicated its use in pregnancy. In 1947, the FDA approved DES use in animal feed and DES use in pregnancy for women with diabetes. Use in pregnancy soon became widespread, with companies marketing DES to prevent miscarriage and other pregnancy complications, and even as a tonic for healthy pregnancies.

The initial medical studies showing a benefit were of poor quality. It is easy to dismiss this as consistent with scientific norms at the time. However, as early as 1941, a letter to the editor in the *Journal of the American Medical Association* critiqued the poor methodological quality of a study claiming benefit from DES use in pregnant women with diabetes. This study lacked a control group not receiving the drug, making it impossible to know if the drug was the cause of claimed benefits. The highly influential 1948 study by the husband and wife team Olive and George Smith at Harvard similarly had no control group, and women were prescribed bed rest and sedation, as well as DES, making it difficult to tease out the effects of the drug from that of other interventions.

Why were the Smiths' studies so influential? And why did they continue to affect prescribing long after more rigorous studies failed to show a benefit?

Both the large double-blind randomized controlled trial by Dieckmann et al., published in 1953, and a second randomized controlled trial by Ferguson failed to show any benefit.

DES Action USA Co-founder Pat Cody comments on the continued prescribing of DES in the 1950's and 1960's despite rigorous, scientifically sound evidence that it was no better than a placebo in her book, *DES Voices: From Anger to Action*. An article by the Smiths on the benefits of DES in preventing complications of pregnancy, *"…was reprinted by many drug companies and carried by their salesmen to the offices of every obstetric practice they visited…. The drug companies did not reprint the Dieckmann article to give to obstetricians, as they had the earlier articles by the Smiths."*

In a meeting of the American College of Surgeons held in Montreal in 1954, George and Olive Smith argued that Ferguson and Dieckmann et al.'s studies had failed to show benefit because of methodological flaws: *"Our error in this study lay*

in not giving a placebo to the controls…. Their error lay in studying heterogeneous groups which were not large enough to show significant differences." The implication of this statement, followed by ten pages of text presenting research results supporting the benefits of DES, is that their research evidence was stronger than Dieckmann's and Ferguson's. The argument that the groups were too heterogeneous and study size too small fails to note the replication of results indicating lack of benefit in two separate randomized controlled trials, and the over 800 women included per treatment arm in Dieckmann et al.

Were researchers unaware of the relative strength in different types of research methods?

The August 1954 editorial by Smith and Smith described above is likely a response to an editorial by Ferguson just five months earlier in the same journal, *Obstetrics and Gynecology*. In this editorial, Ferguson outlines why inherent biases in studies that were not randomized or double-blind appeared to show a benefit: *"…several benefits of stilbestrol have been observed by making comparisons with unsatisfactory controls. These control patients may not have done as well as stilbestrol-treated patients for reasons inherent in their makeup and management."* He goes on to explain why patients who drop out early from a trial also need to be followed up.

Ferguson's editorial on strength of evidence and why poorly designed studies could not be trusted could easily be mistaken for a recent treatise on evidence-based medicine. The Smiths' rebuttal is also hauntingly similar to arguments in commentaries on menopausal hormone therapy that were published after a large randomized controlled trial published in 2002, the Women's Health Initiative, had shown a lack of benefit and increased risks. Documents released in a U.S. legal case showed that these articles had been ghostwritten on behalf of the manufacturer. The common thread with the early DES literature is a misrepresentation of the strengths and weaknesses of the existing body of scientific evidence.

> An interview with an FDA reviewer notes that: "companies routinely sent new remedies to doctors and asked them to try the medicine in patients. Such testing was uncontrolled and entirely anecdotal."

The likely reason that DES continued to be widely prescribed in the U.S. after 1953 was not a lack of scientific expertise within the research community; it was the selective amplification of the message that DES works to prevent miscarriages, prematurity and infant mortality, long after rigorous scientific evidence existed of a lack of benefit.

The FDA's first regulatory failure with DES was not to stick to its initial decision to refuse market approval when there was animal evidence of harm. The second regulatory failure was the agency's inability to ensure that doctors received accurate, balanced, information about the scientific evidence concerning the drug's effects. From 1953 onwards, DES had been shown not to work, yet many doctors continued to believe in the drug's benefits and to prescribe it, and use of DES continued to spread globally. DES VOICE

Unique New Avenue for Sharing the DES Experience

You Can Tell Your DES Story

We hear so often of the need to tell the DES story and now there is a fascinating way to do so. DES Action USA member Sarah Fox has received a research fellowship from the University of Minnesota to create a book-length documentary poem about the physical, emotional, psychological, spiritual and political impact of DES on her own life and the lives of others affected by exposure.

In *Mother Substance*, Fox hopes to use documentary and experimental literary techniques to weave together various texts and stories—including fairy tale, myth, personal histories, scientific/medical literature, media reports, psychoanalysis, ecofeminism, and indigenous incantatory — in order to illustrate the complexity of the DES disaster as well as broaden public awareness of it.

Fox, a DES Daughter herself, is looking for individuals whose lives have been affected by DES, particularly DES Daughters, but also DES Mothers, Sons, Fathers and Grandchildren. For this project she wants to interview those with a stake in the DES phenomenon. Then she'll anonymously incorporate language from the interviews and stories into the project so the speaking voice, the "I" of this long-form poem, is a collective voice that resonates with the entire community.

To learn more about the project itself and to discuss participating in interviews with Sarah Fox via phone, email, or — when possible — in person, email her at dadafox@gmail.com. Our DES stories and emotional responses to living with DES are important and will be woven into the fabric of this creative and stimulating DES poem that is now coming together. DES VOICE

"In America, DES Taken Very Seriously!"

By Cathrien de Brauw

Interesting, sometimes, to step back and see how others view us. We get this insight from a Dutch DES Daughter who wrote about her medical experiences while living in the United States. Quite a counterpoint to the way most of us feel about our health care. Her story was published in the DES Centrum newsletter from The Netherlands, and we reprint it with permission, knowing many of our readers will be surprised, given our own experiences.

My first pregnancy ended in a cesarean section because my son was breech. I was unaware at the time of how lucky he was to be born healthy. I knew my mother had many miscarriages before she got pregnant with me. I also knew of the drugs prescribed to my mother while pregnant with me. What I did not know is the affect they had on me.

The list of the typical Smith & Smith DES regime shines proudly in my baby book, written by my mother, when it still seemed DES was a panacea as to why I had safely arrived.

It was only after my second pregnancy when things went wrong in the 25th week that DES surfaced in a big way in my life. My husband and I were living in the United States. Faced with premature labor, the doctor wanted to put a stitch in my cervix (cerclage) in order to prevent premature birth. But he could not do so because he could not even find my cervix. The delivery was now too far along to postpone and ultimately, my second son was born prematurely in 1982 and unfortunately, died. A beautiful tiny baby boy.

Then the ball started rolling. The fact that my cervix was so extremely short set my American gynecologist thinking. He wanted to know what the cause was and did a hysterosalpingogram. That is a test where dye is injected into the uterus to see how everything looks from the inside. What he saw was an obviously T-shaped uterus. He sat me down and explained that my second son developed in the wrong place in my abnormally shaped uterus, where there was no room for him. He was amazed that my first son had survived my shortened cervix and T-shape.

Later I spoke with my former Dutch gynecologist and asked him about my first birth. I shared the information from my American gynecologist, but I feel he did not take it seriously. According to him, during the first pregnancy there was nothing wrong. In retrospect I think my Dutch doctor just did not know what DES was.

I got pregnant again even though my American gynecologist had warned against it. He said there was a probability that another pregnancy could end in premature birth. In his opinion I should count my blessings and be happy with my eldest son. He spoke from experience, because his wife is also a DES Daughter and with her he had seen a lot of suffering. Moreover, he is American and they are more cautious, anxious.

But I wanted my son to have a sibling, as my family was not yet complete. In addition, my first pregnancy went well, so why not try again? I was lucky, and so in 1984 my third son was born. It was not an easy pregnancy, but thankfully he nestled in the right place in my uterus, just like my first child and all went well.

DES was discussed in my family as I grew up, but the seriousness of my exposure did not resonate with me. Only after I lost my second son to his premature birth did we talk more about it. That is when I became aware of the problems DES causes and the importance of yearly Pap smears. I must credit the Americans. They are careful. DES is taken very seriously there. DES VOICE

Premature Loss of Ovarian Function Linked to DES Used on "Tall Girls"

By Christine Cosgrove
Co-author of *Normal at Any Cost*

A study by Dutch researchers has found that women who were treated with estrogens to stunt their growth when they were girls not only have a more difficult time becoming pregnant, but also lose ovarian function earlier in life than those not exposed to hormones as teenagers.

Beginning in the late 1940s girls in the U.S. who were predicted to grow "too" tall were prescribed DES, and other forms of estrogen, in extremely high doses in an attempt to hasten the closure of their growth plates.

The practice became more prevalent throughout Europe and Australia in the 1960s and 1970s. When the drug was found to cause cancer in DES Daughters, who were exposed before birth, pediatric endocrinologists and other clinicians who treated tall girls heeded the specific warnings about DES and switched to other forms of estrogen.

The Dutch study, published in the April 2011 *Journal of Clinical Endocrinology & Metabolism*, confirmed earlier Austalian findings linking hormone treatment to sub-fertility and noted that treated women more often required IVF than untreated women to become pregnant.

In addition, the Dutch study found that, as the treated "tall girls" aged, their ovaries failed earlier than those of untreated women. The researchers suggest that, as a result, the "tall girls" who were treated with DES and other estrogens should take this into account when working with their physicians in relation to family planning.

Although the practice of stunting growth in tall girls has waned substantially in the U.S. in recent years, it remains somewhat more popular in Europe.

DES VOICE

Scientists Offer Help to FDA and EPA for Safety Testing of Chemicals

So Far The Agencies Show No Interest

By Fran Howell

Federal regulators, those with the responsibility of protecting the health of Americans, have their hands full with an estimated 45-million chemicals available for commercial use. But most have not been subjected to rigorous safety scrutiny.

However, Washington State University Professor of Molecular Biology Patricia Hunt, Ph.D., stepped up to offer help. In an open letter published in the March 4, 2011, issue of the Journal *Science*, she spoke for scientific organizations representing 40,000 concerned researchers and clinicians willing to provide, "appropriate individuals to serve on panels to review and evaluate current programs for effectiveness, to assess the risk of specific chemicals through the evaluation of data, and to develop new testing guidelines and protocols."

According to Hunt, of particular concern are those chemicals with "hormone-like actions." In an interview on the Public Radio International show, *Living on Earth*, which aired March 11, 2011, Hunt told host Bruce Gellerman about current concerns with bisphenol A (BPA) that is used in many plastics and resins that line food and beverage containers. Hunt said, "In the case of something like BPA we have essentially run this experiment in humans before, because DES exposure was that — an experiment in humans…. There are fertility effects and increased cancer rates in those who were exposed to DES. And so we have every reason to suspect that some of these same effects would be seen from chemicals like bisphenol A, the phthalates and other endocrine disrupting chemicals."

Hunt's letter to the FDA and EPA stresses that, "the need for swifter and sounder testing and review procedures cannot be overstated," as we learn more about "direct links between exposures that occur during fetal development and adult disease."

The scientists are willing to put their expertise to use by the FDA and EPA to "help ensure that the most up-to-date scientific methodology and scientific understanding are used when devising and refining regulatory guidelines" for making risk assessment decisions.

And the response to this important offer? Not a word. Hunt tells DES Action USA that no one from either the FDA nor the EPA has shown any interest.

DES VOICE

A Second European Study Shows Birth Defects In DES Grandsons

American Researchers Do Not Get The Same Results

"Prevalence of hypospadias in grandsons of women exposed to diethylstilbestrol during pregnancy: a multigenerational national cohort study," *Fertility and Sterility*, Nicolas Kalfa, et al., available online April 2, 2011.

Reviewed by Kari Christianson

This study by researchers in France focuses on the incidence of hypospadias in DES Grandsons. Similar to a study from The Netherlands published in 2002, the French team found a "significant" incidence of hypospadias (a birth deformity in which the urethra, that carries urine, ends before reaching the tip of the penis) among the grandsons of women who were given DES during pregnancy.

In this French study of 1,000 pregnancies in which DES was given and 180 pregnancies without DES, 8 out every 100 DES Grandsons were born with hypospadias.

The National Cancer Institute (NCI) DES Follow-up Study in their 2005 review did not find a greatly increased risk of hypospadias in DES Grandsons, based on the overall incidence in the United States. According to the Centers for Disease Control and Prevention (CDC), in the U.S. about 4 out of every 1000 boys are born with hypospadias.

In addition to the different findings, there is not complete understanding of the developmental mechanisms that cause hypospadias.

In reporting on this study Reuters Health News sought the perspective of NCI DES Follow-up Study principal investigator and professor at Dartmouth Medical School Linda Titus-Ernstoff, Ph.D. While not involved with the French research, she was able to comment on it and said, "If (defects) are being transmitted to the third generation – and it's not 100 percent certain that they are — we don't know how that's happening."

Among the possibilities listed by Reuters Health was egg damage during the fetal development of a DES Daughter, which then cause the hypospadias defect in her son, or that DES could alter genes and this change could be passed down to subsequent generations. Or, as Titus-Ernstoff is quoted, "It could be nothing."

Even without different findings about the incidence of hypospadias in DES Grandsons, more research is needed to understand ***how*** DES, and other endocrine disrupting substances, harms our health and the environment.

DES VOICE

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In Celebration of DES Mothers

We sat up a bit prouder while reading a post by Dora Calott Wang, M.D., in an article written for the *Huffington Post*. She used the advocacy of DES Mothers to make a case for more involvement by moms in the health care discussion. Here is an excerpt:

Health Reform Needs Moms
Huffpost Health

Posted: March 23, 2011
Dora Calott Wang, M.D.

When it comes to the public's health, moms have a record of getting things done, when the efforts of policymakers and scientists have fallen short.

Between 1941 and 1971, millions of expectant mothers were prescribed DES (diethylstilbestrol), a drug later linked to cancer, infertility, and deformity for the babies exposed in utero, once they reached puberty years later.

DES had been marketed as a pregnancy enhancer, much like pre-natal vitamins are prescribed today. Pharmaceutical companies continued to advertise the drug, and doctors continued to prescribe it, even after a 1953 study showed that the drug conferred no benefit to pregnancy.

Even after DES was linked to cancer in 1971, the prescribing continued.

Only when mothers got involved, did the dangers of DES become more widely known. When Pat Cody read about the link between DES and cancer, she took her daughter, Martha, to be examined. Both she and her daughter were grief-stricken when it was discovered that Martha had a pre-cancerous condition, most likely because of the DES Pat took while pregnant.

Pat Cody founded the organization DES Action, which spread the word about the dangers of DES, and which (works to have research) funded into the impact of DES. Lawsuits were also encouraged. DES is now widely known as a dangerous drug, thanks to the efforts of moms. DES VOICE