

## DES Daughters Exempt from USPSTF Guidelines

**T**he US Preventive Services Task Force (USPSTF) took the concerns of DES Action USA and DES Daughters seriously in creating the newest recommendations on cervical cancer screening.

The recommendations, published in late August, only made one major change to existing recommendations, but they increased the prominence of the information regarding exceptions to the new guidelines.

“Women at increased risk of cervical cancer (ie, women with a history of cervical cancer, a compromised immune system, or diethylstilbestrol exposure) may need to be screened more often,” the recommendations state. “Women who have had CIN 2+ should continue screening for 20 years after the last abnormal test result, even if it extends screening beyond age 65 years.”

CIN 2+ refers to Cervical Intraepithelial Neoplasia Grade 2, a “condition in which moderately abnormal cells grow on the thin layer of tissue that covers the cervix,” according to the National Library of Medicine. “These abnormal cells are not malignant (cancer) but may become cancer.”

When the draft recommendations for cervical cancer screening came out last year, DES Action USA Executive Director Suzanne Robotti and Community Manager Karen Calechman wrote during the

public comment period that DES exposure should be exceptions to the recommendations and that patients who are exceptions should be highlighted, in a larger box or otherwise emphasized. Their concern was that women and health care providers might overlook the exceptions.

The USPSTF listened. DES exposures as an exception is noted several times throughout the recommendations and prominently displayed in a larger box than it previously was.

“Women with these risk factors are not included in this recommendation and should receive individualized follow-up,” the new recommendations state. “Women at increased risk of cervical cancer (i.e., women with a history of cervical cancer, a compromised immune system, or diethylstilbestrol exposure) may

need to be screened more often.”

“We hope that doctors will read this since these are the guidelines that doctors must use if they are going to work with insurance companies to get the screenings covered,” Calechman said.

Since DES-exposed individuals are exempt from the Task Force guidelines, and no guidelines exist specifically for DES Daughters or Granddaughters, DES Action advises that DES Daughters and Granddaughters speak to their physicians about their individual risks.

Arthur L. Herbst, MD, the director of the University of Chicago Clear Cell Adenocarcinoma (CCA) Study and the physician who first discovered the link between prenatal DES exposure and vaginal or cervical clear cell adenocarcinoma gave

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## Psychiatric Disorders May Be More Common Among DES Children

A pair of French studies in the past few years have found evidence that psychiatric disorders, including schizophrenia and depression, occur more often among DES Daughters and Sons than in the general population.

One study, published in 2017 in the French medical journal *Prescrire International*, queried 2,566 DES Daughters and 2,967

women not exposed prenatally to DES. Just over a quarter of the DES Daughters (26%) reported having a severe mental health condition or needing to consult a psychiatrist, compared to 16% of the unexposed women.

Even after making adjustments to take into account other factors that could have influenced those

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# Gender/Sex/Sexuality and DES Exposure

## Part 4: Barriers to Accessing Health Information and Care


**Jacquelyne Luce (Lecturer in Gender Studies) and April Albrecht (Gender Studies major and Frances Perkins Scholar), Mount Holyoke College**

A priority of this research project is to highlight the experiences of people and topics that were marginal to the DES movement. One of our concerns is to try to understand how people's knowledge or speculations about DES exposure in combination with lived experiences that differ from societal norms of gender, sex and sexuality might affect their access to DES-specific health information or care.

A transman who became aware of his DES exposure in his early 20s, and who underwent a gender change in his late 20s, noted the conundrum he now presents in encounters with healthcare professionals. He has

taken testosterone for approximately 30 years, had his ovaries and uterus removed about 12 years ago, and has a vagina. When asked whether he has followed any recommendations for DES-specific screening or care, he responded: "No. I have found that all of my physicians today are totally bewildered by what standards [e.g., male or female] they should hold me to. [...] I think that the other issues, the trans issues, are so overwhelming when it comes to [lab] testing [...] that the DES stuff just gets left by the wayside." He told us that he had had regular gynecological care up until he changed his gender. But then, he recalled, "I looked so male, I could not get a gynecologist to look at me." Assumptions about who belongs in which healthcare sites (like a gynecology practice) led to nearly 20 years without gynecological care.

Another interviewee, a DES-exposed cisgender (i.e., non-transgender) woman, experienced atypical hair growth (hirsutism) in her late teens/early 20s, shortly before finding out she had been exposed in utero to DES. "I was struggling, going to endocrinologists trying to get my physical body back into the shape I wanted it—without so much hair—and then I really wanted a boyfriend. It was very confusing and very tough." She recalls that years later, as she tried to make sense of her experience, a lesbian acquaintance, also DES-exposed, recommended a DES-Trans listserv noting: "It's actually for transgender people, but there's a lot of information on there that you're not getting on the DES Daughters list." It was on that list that she found ideas being shared about DES exposure, sexuality, and gender variance which seemed more relevant to her situation.

These examples illustrate barriers to accessing health information and care. Due to his transgender body and identity, the interviewee in the first example did not participate in the forms of DES screening recommended for people with ovaries, a cervix and a vagina, screening that cisgender interviewees often viewed as of continuing importance. The second example highlights how a cisgender woman, who found her questions unaddressed or marginalized by the focus of the "mainstream" DES Daughter forums, sought access to information in a forum developed for DES-exposed transgender people. As we continue our research, we are aiming to make such complexities of intersecting identities and experiences visible and relevant to ongoing education, advocacy, and research related to DES exposure. 

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# Does DES Cause Hip Dysplasia?

## *Perhaps Indirectly in the Third Generation*

Some DES Daughters, Sons and Grandchildren have experienced problems related to their bones and joints, such as mild hip dysplasia, that has led them to ask whether DES may have contributed to those problems. Hip dysplasia is a condition where the hip ball joint does not sit properly in the hip socket as it should, sometimes resulting in partial or full hip dislocation.

It's a condition present at birth, though it often goes undiagnosed until adolescence or early adulthood. Hip dysplasia accounts for up to one in 10 hip replacements in the US, according to the International Hip Dysplasia Institute.

Today, no known, published human studies have specifically examined whether hip dysplasia occurs more frequently in those exposed prenatally to DES. But two separate pieces of research, one in DES Grandchildren and one in mice, suggest how DES may directly or indirectly contribute to musculoskeletal issues. We will report more about the musculoskeletal issues in the next issue. But research in DES Grandchildren suggests how DES may indirectly contribute to hip dysplasia.

### **Hip Dysplasia in DES Grandchildren**

Research by Linda Titus, PhD, a professor of epidemiology and pediatrics at the Geisel School of Medicine at Dartmouth, found an increased incidence



of hip dysplasia among DES Granddaughters. In Dr. Titus's study on birth defects in children born to DES Daughters, hip dysplasia was among birth anomalies reported by DES Daughters in their sons and daughters.

That study did not break out hip dysplasia rates separately from other skeletal issues, but

more common in the prenatally DES-exposed mothers of third generation women."

For example, breech babies—those with their buttocks instead of their head facing down at birth—have a higher risk of hip dysplasia. According to the International Hip Dysplasia Institute, the way an infant sits in the womb can affect pressure

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**'Hip dysplasia can be caused by pregnancy or birthing difficulties, which were more common in the prenatally DES-exposed mothers of third-generation women.'**

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mothers reported higher rates of any skeletal problems in DES Granddaughters and DES Grandsons compared to children whose mothers were not exposed to DES.

Among 2,640 DES Grandsons and 1,389 boys born to unexposed mothers, 0.8% of the DES Grandsons had skeletal birth defects compared to 0.5% of the unexposed boys. Similarly, among 2,449 DES Granddaughters and 1,359 girls born to unexposed mothers, 1% of the DES Granddaughters and 0.4% of the unexposed girls had skeletal issues at birth.

Regarding hip dysplasia in particular in DES Grandchildren, it may be an "indirect consequence" of their mothers' DES exposure, Dr. Titus explained.

"DES didn't directly cause the hip dysplasia through some biological mechanism," Dr. Titus said. "Hip dysplasia can be caused by pregnancy or birthing difficulties, which were

placed on the hip and therefore possible risk of hip dysplasia. The Institute also noted how hormone levels might affect risk.

"Around the time of birth, the mother makes hormones that allow the mother's ligaments to become lax (stretch easier) so that the baby can pass through the birth canal," the Institute states. "Some infants may be more sensitive to these hormones than others, allowing for excessive ligament laxity in the baby. Girls usually have more ligament laxity than boys and girls are 4–5 times more likely to have hip dysplasia than boys."

No human research so far has explored whether DES potentially interfered with hormones to affect hip dysplasia risk, but a theoretical risk exists.

Source:

*Birth Defects in the Sons and Daughters of Women who were Exposed in utero to Diethylstilbestrol (DES)*. 2010. doi: 10.1111/j.1365-2605.2009.01010.x

DES VOICE



# Q&A with Early Members

*In honor of the 40th Anniversary, we've been asking some of the early members of DES Action to reminisce about the early years and how being involved with DES Action changed their lives  
Thanks to all who have contributed.*



**Carla Childs**

"There was no organization when we started. It was 1974 or 1975, and I felt the need for support, so I put up posters around the University of Pennsylvania campus asking, 'Are you a DES baby?' We scheduled a meeting, and we decided to become a group.

We found other groups springing up, and that was exciting. We were trying to provide support for each other and have an advocacy group at the University of Penn DES Center to be able to stand up for ourselves when we were being examined and feeling vulnerable. I knit myself a pair of thigh-length yellow and orange "colpo-socks" so I could go into my colposcopies and keep my legs warm.

We were also trying to deal with Eli Lilly and to stand up for ourselves there, and we were being heard. I remember that the poor nurses at the DES Center felt we were being fierce and said, 'But we're trying to help you.' We were just angry that we had to be there at all and were taking it out on them. We realized that we needed to

rethink our approach there. It was a very exciting time to be starting something new."



**Martha Cody**

"One of my early memories of DES Action is of serving as the 'human subject' for a pelvic exam at the Berkeley Free Clinic. I was up on the table with my feet in the stirrups as various clinic providers watched in fascination. It helped a lot that my mom, Pat Cody, stayed in the room with me throughout the exam.

I also have fond memories of going to Washington, DC, with many others to lobby Congress for continued support for DES research by the NIH, probably in the early 1990s.

I hope that DES Action continues to collaborate with medical researchers to extend their studies in areas like third generation effects and gender identity, in addition to maintaining the listserv to facilitate communication and support among the DES exposed."



**Joanna Katzen**

"When I first joined DES Action, I was a starving college student. I had no funds and was desperate for information. The board approved my membership even though I couldn't afford the fees, and the help, support and information I've received over the years are extremely valuable and helpful. The members of the listserv provide the greatest support system, and I am consistently grateful for them."



**Litsa Varonis**

It was Fall 1976, and I was in my first semester of grad school at the University of Pennsylvania, a

young 21-year-old teaching English as a Second Language on a teaching fellowship. Carla Childs, newly arrived back home after spending two years with the Peace Corps, was teaching the same group of students, so I was happy to benefit from her insights and experience.

She invited me to walk with her one day after class as she posted flyers in women's bathrooms in Houston Hall, flyers that offered local support from a Penn-sponsored organization to women exposed to a drug called DES. "You should ask your mother if she took that drug," Carla suggested. "She's not the type to have taken anything while she was pregnant," was my confident response.

And I didn't give it another thought until the spring, after Carla's wedding. My mother had never attended a Quaker wedding and asked to accompany me to the ceremony. Very impressed with Carla and her family, Mom asked me what else she was involved with. I told her that Carla coordinated a DES support group for Philadelphia. "What's that?" Mom asked...and the next day she told me I was exposed.

Amazingly, she had received a letter from her retired ob/gyn a year earlier telling her of possible risks to DES-exposed daughters. She called the provided number and said a nurse assured her that since she took it early in the pregnancy there was nothing to worry about. She did not work up the courage to tell me until she found out I already knew something about it. It was a traumatic evening—my first exposure to Adult Onset Guilt—and only the second time in my life that I saw my father cry.

Carla lent me the bright orange thigh-high socks she had knit for herself for my first colposcopy at the DES Center of the University of Pennsylvania, a colposcopy that took forever. The nurse/colposcopist's first words were "I can really tell your mother took this drug." She

also shared that I had more adenosis than anyone she had ever examined.

I still remember the "Dare to be different" poster on the wall of



the exam room, a caricature of a rooster with a hair comb instead of a cockscomb on its head (and yes, I had a prominent cervical cockscomb, too).

Shortly after, both my parents attended with me an evening seminar on DES that involved many DES-exposed individuals and included medical and legal information. But they were adamant I could not share anything with any friends, especially friends in our ethnic community, since if word got out "no one will want to marry you." Their intentions were good, but I desperately needed support.

That support came from individuals like Carla and others whom I met through her, through the local organization, and very shortly after as the grassroots groups unified in 1978, through DES Action. I still have my original "Ask Your Mother" pin. I also have copies of the constantly-evolving printed literature that I received from DES Action initially and then, as a DES Action co-coordinator in Michigan, ordered from headquarters myself for distribution to others.

Through DES Action, I have received support and I have offered support, face-to-face, over the phone, through letters, through emails, through listservs, at press

conferences and via organized presentations in multiple states, some of which I've organized myself. Conversations evolved from fears of cancer to challenges related to conception, pregnancy loss and premature delivery, to continued risks to the DES-exposed mothers, daughters, sons and now grandchildren.

And in 1985, after my marriage and birth of my first child, my mother took courage and appeared next to me and others from DES Action Michigan in a televised news segment announcing DES Awareness Week in that state. This was huge and never would have happened without the organizing force of DES Action.

For me, DES Action has served as an emotional and information support group as well as a model of advocacy and a bold catalyst for research and policy change. As a former board member of DES Action, I was awed to sit in the 2000s at Pat Cody's oak table, a table that had hosted so many dedicated, bold leaders dating back to the '70s, including Carla Childs the year DES Action was born.

That oak table for me is a metaphor for the organization: strong, unvarnished, unpretentious, an even surface and solid foundation upon which to build, vote, draft, brainstorm and unify good people with good intentions, even though we didn't always agree with each other.

Happy 40th Anniversary, DES Action.

### Shelly Slatz

"When I received the information about joining DES Action in 1978, I felt like it was a lifeboat. For years, DES exposure felt like a time bomb, and receiving the DES newsletters helped me through those difficult years and still remains the only reliable source of information. I am grateful that MedShadow has helped DES Action to flourish."

DES VOICE

# Dr. Anne Cabau, DES Whistleblower, Dies at 81

One of the most important figures in DES history, Dr. Anne Cabau, passed away July 2 in Paris at age 81. Dr. Cabau was the French whistleblower whose work led to uncovering the pharmaceutical disaster of prenatal DES exposure in France. An estimated 160,000 French children had been prenatally exposed to DES, prescribed primarily from 1964-1972.

Dr. Cabau, who had done her medical training in the United States, read about the dangers of DES in published US medical research. While the US had banned use of DES in pregnancy in 1971, it continued to be used in other countries, despite no evidence showing benefits and a growing body of evidence showing its harms. As an infertility specialist, Dr. Cabau began collecting data on the malformations that occurred in



Dr. Anne Cabau

uteri to women exposed to DES in the womb in France.

She published her findings in 1982 in the scientific paper “Uterine malformations in girls exposed to Distilbene during their embryonic life: Consequences on their fertility.” Distilbene was the brand name for diethylstilbestrol

in France at the time. The paper came out 11 years after Dr. Arthur Herbst’s seminal 1971 research showing the link between DES and clear cell adenocarcinoma.

Her research was then highlighted in a 1983 news article, “A Monumental Medical Error: The Children of Distilbene,” which immediately made waves in the national press. Yet it took another six years, in 1989, for the French Ministry of Health to first publish guidance for physicians caring for patients exposed to DES.

Meanwhile, Dr. Cabau was initially ostracized from the medical community for a time, and the College of Physicians even received a formal complaint about her that was eventually recalled. Dr. Cabau served as a member of the Scientific Advisory Board of Réseau DES France, the French DES advocacy and education organization. **DES VOICE**

## Psychiatric Disorders More Common Among DES Children

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findings, the odds ratio indicated that DES Daughters remained nearly twice as likely to develop a psychiatric condition as unexposed women. Partial explanation for this finding may rest in the experience of managing the various problems prenatal DES exposure can cause.

“DES Daughters were more likely than women in the control group to have a history of infertility, nulliparity, spontaneous abortion, fetal death or cancer,” according to an editorial published May 2018 in *Prescrire International*. “However, DES daughters and unexposed controls who had faced one or more of these difficulties were equally likely to have consulted a psychiatrist.”

The other study was not peer-reviewed but came from a survey

administered by the French patient support group HHorages to 529 DES Mothers about their combined 720 DES Children.

That study found that more than half the DES Sons and Daughters reported a psychiatric disorder, and 32 of the children died by suicide. In a separate group of 262 children whose mothers took DES but only in a previous pregnancy, a much lower rate of psychiatric disorders (6%) was reported along with one death by suicide. The researchers also assessed 180 children whose mothers only took DES in a subsequent pregnancy after they had given birth to those 180 children. No psychological conditions or suicides were reported among those 180 unexposed children.

“Recruitment through a patient support group is likely to overestimate the frequency of disorders,” noted the new *Prescrire*

*International* article. “Nevertheless, these data provide an insight into the types of psychiatric disorders observed in exposed children.”

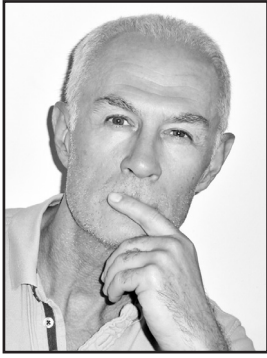
The most common condition reported among DES Sons was schizophrenia, followed by mood disorders (depression, anxiety, bipolar disorder) and behavioral disorders, including violence, aggression and obsessive-compulsive disorder.

Among DES Daughters, depression and bipolar disorder were the most common psychiatric conditions reported, followed by eating disorders, behavioral disorders, obsessive-compulsive disorder and schizophrenia.

“Taken together, the evidence makes a plausible case for a psychological component to the long-term harms of exposure to DES during pregnancy,” concluded the *Prescrire International* article. **DES VOICE**



# *'It's time to Finish with "Dodging" or Shame.'*



Laurent

*"On the contrary, it's about time we denounce injustice, like our female colleagues who have been fighting for so long now."*

That is what Laurent replied when we asked him if we could publish the message he had written when he joined Réseau DES France. Reprinted with permission.

Hello to you all,

I've just recently joined your organization, after hesitating for several years and finding sufficient

information before making the move and joining.

I was born in 1961; my mother had a difficult pregnancy, and I am a DES Son. I didn't know about this until very late in my life, as it was probably a taboo subject: my mother never mentioned it.

Because of my asking her questions, I realized that my mother had taken prescriptions (for DES) from Paris doctors at that time.

For me there have been many different consequences during all my life:

- I was born prematurely, with late descent of testes, nipples growing during puberty,
- penis smaller than the norm and, worst of all, is sterility.
- my kneecaps are too high, which has meant several operations (with no cartilage now, hence a handicap)
- esophagus too short, with gastric reflux all my life, and numerous esophageal ulcers (requiring treatment for all my life); general fragility of the joints.

I'll not talk about the mockery I received regularly from those near me because of my "physical weakness" and "ailments." They used to call me a "sissy" when my "difficulties" were mentioned...

This continued the massive problems I've had to face up to all my life, because of this "junk."

I've accepted all this as it is, because, in the '60s, '70s and later, it wasn't in the mentality of French society to be litigious, and even less so in my family.

Today I want to emerge from my silence and fight to get recognition of my problems and obtain reparation for all these prejudices.

Thank you (Réseau DES France) for your actions and thank you for existing.

Laurent

P.S.: My mother has sadly just passed away from cirrhosis of the liver. She never drank. I don't know if it is a direct consequence of taking DES or if there is no link.

## **DES Daughters Exempt from USPSTF Guidelines**

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a statement to DES Action USA about what he recommends.

"Even in the absence of a Pap smear, the DES-exposed woman should have an annual pelvic exam where her physician fully views the vagina and cervix," Dr. Herbst said. "We do not have enough data to definitively say or support that there is no upper age limit on CCA diagnoses. Since it is not known yet, this should lead to the continuation of annual exams."

Indeed, a 70-year old DES Daughter was recently diagnosed with CCA. "Even if the Pap smear isn't done annually," Herbst said,

**'We do not have enough data to definitively say or support that there is no upper age limit on CCA diagnoses. Since it is not known yet, this should lead to the continuation of annual exams.'**

"an annual pelvic exam is higher priority for DES Daughters." In line with the guidance that has been used for DES Daughters for the past few decades, DES Action recommends an annual four-quadrant Pap smear and a palpate exam. Even those who have had a hysterectomy need an exam if they still have a cervix or a vagina because the clear cell adenocarcinoma that poses the

most risk to DES Daughters is vaginal clear cell adenocarcinoma.

These clarifications by USPSTF can be used by DES Daughters to ensure Medicare fully covers their screening services. Since DES-exposed women are an exception to the new recommendations, they are entitled to insurance coverage of thorough screening for their risk level, including past age 65. **DES VOICE**

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*Return Service Requested*

**Join DES Action monthly  
on Facebook Live!**  
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## Join Us for Our Facebook Live Interviews

It's been a remarkable 40th anniversary year of Facebook Live conversations, and it's not too late to join us for the final ones, or check out the previous ones archived on in the Members Area of [desaction.org](http://desaction.org).

**January**—StupidCancer founder Dave Fuehrer discussed his app, which includes a section for the DES-exposed community.

**February**—DES Daughter and Peabody Award-winning documentarian Judith Helfand discussed her film *A Healthy Baby Girl*.

**March**—Author Susan Bell discussed her book *DES Daughters: Embodied Knowledge and the Transformation of Women's Health Politics in the Late Twentieth Century*.

**April**—DES lawyer Michael London discussed the current state of lawsuits and what actions are still possible.

**May**—Jacquelyne Luce, PhD, discussed her research project "Embodying Transgenerational Exposure: Gender/Sex/Sexuality and Experiences of Being DES-Exposed."

**June**—Nita Karnik Lee, MD, who specializes in gynecologic cancer, discussed the latest on clear cell adenocarcinoma.

**July**—DES Daughter Susan Helmrich discussed the DES Cancer Network she co-founded.

**August**—Former DES Executive Director Fran Howell and retired Program Director Kari Christianson discussed the formation of DES Action.

**September**—DES researcher and Dartmouth professor Linda Titus, PhD, discussed research on the third generation (DES Grandchildren).

**October**—DES Mother

Linda Greenebaum discussed her grandson's ADHD diagnosis with her DES Daughter.

On Nov. 24 at 4 pm (ET) we will talk with Gary M. Levine, radiologist and mammogram specialist. He will explain some techniques appropriate for DES Daughters. The final Facebook Live is a special Town Hall event on Wed., Dec. 12, with DES Executive Director Su Robotti and Community Manager Karen Calechman. Join them with your comments and questions as they discuss their work and future plans for the organization.



**DES VOICE**