

## Sons of DES Sons May Have Higher Genital Defect Risk

**B**oys born to DES Sons appear to have an increased risk of micropenis and undescended testicles, found a recent small study out of France. The study population was small: just over 200 DES Grandsons born to fathers prenatally exposed to DES, and only six DES Grandsons showed these problems.

But, if future studies confirm these findings, it suggests physical effects on genitals from DES may continue into the third generation, depending on the biological sex of the DES-exposed parent and the DES Grandchild.

“This transgenerational effect, already observed in animals and in the offspring of women prenatally exposed to DES, could be the result of epigenetic changes transmitted to the subsequent generation through men,” wrote lead researcher Michel Tournaire, of the Université Paris Descartes in France, and his colleagues. The study was published in March in the French medical journal *Thérapie* (doi:10.1016/j.therap.2018.02.007).

In simplified terms, epigenetic changes are those that result from “turning on” or “turning off” the expression of different genes. Two people with identical genetic code could show very different characteristics or different health circumstances if those genes are expressed in different ways. Proteins that flip a gene’s switch in one direction or another can be

inherited and can be influenced by environmental exposures.

Past research in animals has shown that DES can affect gene expression into the third generation. Some studies, for example, have found more frequent reproductive tract defects in female mice born three or sometimes more generations after a DES-exposed parent mouse. But scientists are only starting to learn what effects might occur in third generation humans (DES Grandchildren).

At least two other studies have found a slightly higher rate of overall birth defects in children born to DES Daughters compared to children of unexposed women. The VOICE previously reported on research finding that boys born to DES Daughters have a higher risk of hypospadias, a birth defect in which

the opening to the urethra (the hole that urine and semen exit the body) is on the underside of the penis instead of the outer tip.

The current study came about through a French DES patient association with funding from the national French Drug Agency and the country’s national health insurance program. The researchers used questionnaires from 325 DES Sons to assess possible birth defects in their 405 children, including 196 daughters and 209 sons.

Those 209 DES Grandsons were compared to the general population in Europe, to children born to DES Daughters and to sons of women not prenatally exposed to DES. (The researchers did not have a group of boys born to unexposed men to use as a comparison group, which is a

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## Did DES Cause Autoimmune Disease? Possibly — But It’s Complicated

Autoimmune diseases result from the immune system attacking itself, mistaking cells or tissue for potentially dangerous invaders. Environmental exposures can trigger immune system overreactions, such as allergies and asthma. Extra pollen, for example, can cause the immune system to overestimate the danger of pollen particles and

go after them like an army tank attacking a housefly.

The immune system interacts closely with the endocrine system, which helps regulate immune response. Since DES is an endocrine disruptor, it’s theoretically possible it could interfere with the endocrine system in ways that affect

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# Gender/Sex/Sexuality and Experiences of Being DES-Exposed

## Part 2: Notes on Terminology

**Karisa Poedjirahardjo (double major in Gender Studies and Theatre) and Jacquelyne Luce, PhD, Principal Investigator and Visiting Lecturer in Gender Studies, Mount Holyoke College**

*Every Monday afternoon, I [Karisa] take the 1:05 shuttle to the Sophia Smith Collection at Smith College, home of the DES Action USA archive. I am a student member of a research team exploring the intersections of DES exposure and experiences of gender, sex and sexuality by studying documents in the DES Action USA Archives and interviewing DES-exposed individuals. I have struggled with the archival material, feeling like I was missing something, wasn't reading close enough, or worse, that I wasn't smart*

*enough to find the answers. There simply weren't any mentions of sexuality and gender variance in the material that I was reading. How were we supposed to do our research?*

The words gender, sex and sexuality hold different meanings to people in their everyday lives. In the field of Gender Studies these terms are central to our attempts to understand social relationships and societal norms. **Sex** often refers to sexual difference on a biological level (anatomy, chromosomes, hormones), whereas **gender** often refers to cultural expressions of identity, in particular in relation to femininity and masculinity. Creating a distinction between the two enabled feminist scholars to

explore the ways in which gender was expressed and experienced in culturally specific ways, even if sex seemed to be pretty universal. **Sexuality** is intimately tied to both of these terms and associated with feelings and acts related to sexual desire or lack thereof. These terms are often used interchangeably, and many would argue that our understandings about sex are just as cultural as our ideas about gender.

### Including the 'Queer' Experience in DES History

The word **queer** has been reclaimed by lesbian, gay, bisexual, transgender and intersex communities as an empowering term of identity. One can talk about queerness—in terms of sexuality or gender expression—without necessarily attaching the term to LGBTQI identities. Queer can also be used as a verb. By paying attention to the experiences of people who historically were not as visible within the DES Action movement, our project is **queering** the history of DES and the archive.

Jen Bolmarcich, the archivist who processed the DES Action USA Archive, took an initial step to queering the narrative of DES exposure by fairly consistently referring to DES Children, rather than DES Daughters and Sons, in her description of the collection. This can avoid unintentionally excluding people who may not identify with the gendered categories and/or their assumed biological meanings. Jen Bolmarcich also points researchers to Box 2 of the collection, noting

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# Q&A with DES Daughter Andrea Tabor



Andrea Tabor

Andrea Tabor was 16 when she learned that her mother had taken DES while pregnant with her. Andrea's mother had had a miscarriage before Andrea and was prescribed DES to help retain her second pregnancy. After seeing the news stories, Andrea's mother took her to her gynecologist. Although the exam found nothing concerning, he recommended regular visits since so little was known about prenatal exposure at that time.

Andrea feels fortunate that her mother took the lowest possible dosage and only during the first trimester, perhaps saving Andrea from many of the problems experienced by other DES Daughters.

It was not until many years later that Andrea learned, through an article in the DES VOICE, that a drug she was prescribed at age 12 to slow her height growth was also DES. She has therefore been exposed both in the womb and as a young adolescent.

## **Q: Why were you prescribed DES for your height?**

I'm 6 feet tall as an adult. At age 12, I was already 5'7". A woman growing to this height at that time period (I'm 70) was very unusual. When my mother took me to an endocrinologist, the doctor said if she had brought me in when I was 10, he would have been able to help lower my height. He took x-rays and measurements of my

knees and my wrists to predict my growth. He said I originally would have been 6'4" if he hadn't given me DES. In three years I grew to 6 feet tall, which was crazy, but I did stop growing at age 15.

We didn't know it was the same drug at the time. When I found out through the VOICE newsletter, I was shocked. I had to calm myself down. I read it maybe two or three times, and I remember even calling to verify that what they printed was true. I just had to accept it. I can't get it out of my system.

## **Q: What health problems can you trace to DES exposure?**

In my teen years I had a lot of vaginal infections that I think were caused from the DES. But I've been lucky because I'm not dead, and I haven't had worse things happen to me. No cancer—knock on wood—although I had infertility problems probably related to DES. I've had five pregnancies and one live birth. I had three miscarriages before my son, then gave birth to my son, then another miscarriage, and then I said that's it, I'm done.

Ironically, I was given Clomid for three months in 1978 to help me get pregnant because testing showed I didn't ovulate every month. Six months later, I was pregnant with my son. But Clomid is a synthetic drug with estrogen-like properties (like DES but weaker). I took a medication to treat a problem that was caused by a similar medication type in the first place!

I also remember going on the Pill when I was 20 or 21, and I temporarily lost my hearing, probably related to the DES. My gynecologist said I needed to get off the Pill, and then six months later, my hearing came back fully.


## **Q: How has your DES Action membership affected your life?**

Every year I renew because I believe in it. Knowledge is power, and DES Action has made me more aware of the medical community and pharmaceutical companies and not to be so trusting. In my mother's day, whatever the doctors said was gospel. By the time it got to me, I had already learned too much, and I learned to speak up. I know the FDA runs this country, and I think they bow down to the pharmaceutical companies. I think we need to challenge them more, or we're never going to get anywhere.

## **Q: In what ways has being exposed to DES impacted your life over time?**

I have changed my whole way of thinking and how I lead my life. I try not to live in fear, but it's always in the back of my mind. I don't trust pharmaceutical companies at all. I think they're all liars, there to make money and push their product. I eat organic food, with less pesticides, and I don't eat beef.

I have great doctors, but if they're not all willing to talk with me, I will see another doctor. I have fibromyalgia, which may be part of the DES exposure along with migraine headaches I get, so I'm very careful about what I eat and when I eat it, because there are a lot of triggers. I saw this primary care doctor recently, who just wanted to dole out medication. I didn't want to take it. She said, "Then I can't help you," and I said, "No, you can't," and I went to someone else.

I've learned to open my mouth and be more proactive. I'm also a Neighborhood Watch Captain, and the Anaheim police have given me an award because of the impact and improvements I have made in my community. This is the person I've become. I'm not shy anymore, and if I don't like something, you're going to know about it. 



# Early Members Share Memories & Hopes

*In honor of the 40th Anniversary, we've asked some of the early members of DES Action to reminisce about the early years and how being involved with DES Action changed their lives.*

*Who did we miss? Please send in your suggestions and we'll do our best to include as many as possible. Email [Karen@desaction.org](mailto:Karen@desaction.org)*



## **Laura Schlesinger Minor, '56**

DES Action not only gave me the support and information that I needed upon finding out that I was DES-exposed, but it also became my school for community activism. In 1979, I was newly married, a brand new physician's assistant with some undiagnosed gynecological problems and the knowledge that DES exposure could mean vaginal cancer. DES Action taught me how and where to educate myself and how to know if my gynecologist was competent to treat me.

I connected with Christine Witzel, another DES Daughter, and together we began DES Action Connecticut. I learned how to write press releases, do public speaking, start a nonprofit, run support groups and more, always with skilled support a phone call away. I met the early activists—Pat Cody, Joyce Bichler, Andrea Goldstein and others—and helped start a chapter in Los Angeles after moving there. Those early experiences gave me confidence and satisfaction in the knowledge that I could make a difference. With a new group of activists back

in Connecticut, I helped to get a law passed preventing insurance discrimination for DES Daughters and Sons while pregnant with my miracle daughter.

DES exposure affected my own health in many negative ways, but DES Action provided me with courage, peer support and lifelong skills as an activist. Through the early days of DES Action and inspiring leaders, I became more than an informed victim: I became someone who was empowered to make real change.



## **Linda Marks, '56**

I went to a local DES Action meeting around 1980 and ended up joining forces with the organizers, Laura Minor and Wendy Votroubek, running the local Los Angeles group until I moved to Washington, D.C. in 1982. We'd do PSA announcements, hold meetings at hospitals or other public spaces and provide literature and give presentations to mothers and daughters. The first meeting I went to was with my mother, and we were the only mother-daughter duo there, which surprised us.

Turns out some mothers knew they were given DES but still couldn't tell their daughters, and some daughters had nothing but anger or resentment toward not only the medical establishment, but also their mothers. My mom will soon turn 97, and I cherish the fact that as we learned about DES and its effects, we dealt with it together.



## **Andrea Goldstein**

In 1978, I began volunteering for what would soon become DES Action. At 25 years old, I was already struggling with DES-related infertility, having had an ectopic pregnancy in the fall of 1976 and a miscarriage of twins in 1978. My uterus had been badly deformed by DES and had virtually no cavity. At that time, I knew nothing about grassroots organizing, public education campaigns, or how to work with the media. What struck me was how alone I was with my pain. I knew no DES Daughters; none of my friends had yet married. In fact, that DES caused uterine deformity would not be mainstream knowledge until about 1982, and getting people to know what had

happened to me, and why, became the driving force in my life. These few brave pioneering DES mothers, and their cause, welcomed me, and I knew I had found a home. My DES advocacy spanned nearly 25 years. It is a rich legacy, and I am honored to have been a part of this effort from its earliest beginnings.



**Jackie White, '63**

In 1981, I was researching some gynecological information on some symptoms I was experiencing. Although I was aware of my exposure, I hadn't completely made the connection that they were related to DES. I discovered the DES Action site and found a lot of helpful information. I also found a knowledgeable gynecologist and remained in his care until he

retired in 2000. DES Action led me to the best option for care I needed.

I hope DES Action remains current and informed on the impact of exposure on the children and grandchildren of those like me who were exposed in the womb. My son and his wife are expecting my first grandchild, and while we are excited and blessed about that upcoming birth, I know the challenges they faced trying to conceive. I worry those issues were related to my DES exposure, since my son was the reason they needed to use IVF. We owe knowledge to the next generation of people exposed.



**Fran Howell, '51**

When I was named to the DES Action USA Board of Directors,

my mom was pleased. But what she really wanted to know was, "Did you meet Pat Cody?" To Mom and so many others in the U.S. and around the world, Pat was a superstar. She didn't think she was special—yet everyone else knew she was.

I did get to meet Pat, and came to feel that I was in the company of greatness when with her. Pat made it her business to know what was happening so that she and the rest of the DES Action activists could convey accurate and timely information to the DES-exposed community. There was nowhere else to turn for it. Pat never sugar coated the facts, and often the news wasn't good. But her word could be trusted, and so Pat became widely known as the go-to person regarding DES exposure. My mantra during my time as Executive Director of DES Action was: What Would Pat Do?

Interestingly, even though we now tend to think of our organization as mostly by and for those who were exposed to DES before birth, it was primarily our mothers who were the driving forces in the early years. And the one who came to be thought of as "The Mother of Us All" was Pat. **DES VOICE**

## **Gender/Sex/Sexuality and Experiences of Being DES-Exposed** *continued from page 2*

discussions about gender identity and sexual orientation that are contained in the 2001-2002 Board Meeting minutes. Correspondence in this folder includes calls for increased attention to, and representation of, the experiences of DES-exposed men and transgender women. **Transgender** is a term used by many people who do not identify with the sex/gender that they were assigned at birth. Some transgender people transition, identifying primarily with a gender that is different from

what they were assigned at birth. Some transgender people choose not to identify with the categories of woman or man. Some people identify as **nonbinary**, also resisting the social categories of woman or man. **Cisgender** has emerged as a term referring to people who do identify with the gender/sex assigned to them at birth. **Intersex** is a term used by many people whose anatomy, hormonal, or chromosomal status does not align uniformly with that which is usually expected of females and males. In our research, we are noting that many characteristics, both internal and

external, which are understood to be effects of DES exposure are also experienced by intersex communities: e.g. infertility, genitalia or sexgender markers variations in or girlhood and womanhood without a vagina.

Our interviewees are thinking with us about how DES exposure relates to the broader context of their lives and the environment, sharing ideas about how it is or may be related to their experiences of being intersex, transgender, a woman, a man, asexual, bisexual or straight. We look forward to sharing more about this project throughout the year. **DES VOICE**

## **Sons of DES Sons** *continued from page 1*

weakness in the study.)

Birth defects occurred in 3.5% of children born to DES Sons, including three cases of cryptorchidism (undescended testes), two cases of hypospadias, and three cases of hypoplasia of the penis (micropenis) in the boys.


Boys born to DES Sons showed more than five times greater risk of undescended testicles and nearly 23 times greater risk of micropenis. However, despite how large and disturbing these numbers sound, there are important caveats to keep in mind. First, the range of possible risk varies a great deal; that's common when a study population is too small to identify a more precise, reliable risk estimate.

For micropenis, this study population's risk was 23 times greater. However, micropenis only occurs in about 3 of every 20,000 boys born. A 23 times greater risk means 69 out of 20,000 boys fathered by DES Sons—only about 0.3%—would have a micropenis.

Further, the statistical analysis showed the actual increased risk in a large population could range anywhere from four times greater (12 out of 20,000, or 0.06%) to more than 100 times greater (about 1.5% of DES Grandsons). Such a wide range means scientists need to do further research with a larger group of study participants or other populations. The range for undescended testes was not quite as large—about 1.5 times to nearly 22 times greater risk—but it still spans

broadly enough to show a need for additional study.

Perhaps surprisingly, no increased risk of hypospadias was seen among boys born to DES Sons even though it has been seen in sons born to DES Daughters. In addition, the daughters born to DES Sons showed no risk of genital birth defects. The study had other limitations as well.

“Data on pregnancies and their outcome should probably be less accurate when reported by prenatally exposed men than by exposed or unexposed women,” the researchers wrote. “In particular, men may report information mostly on their living children when women should also consider pregnancy complications including perinatal death with possible malformations.” 

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## **Did DES Cause This?** *continued from page 1*

immune system functioning.

In early studies, mice exposed to DES showed increased risk of autoimmune disease, but later human studies have been contradictory. The first three studies examining possible DES effects on the immune system suggested autoimmune disease was possible but did not confirm it as a definite DES effect.

Then a large 1988 study, “Increased occurrence of autoimmune disease among women exposed in utero to DES,” compared cases of autoimmune disease among 1,711 DES Daughters and 922 unexposed women. The researchers found 2.9% of DES Daughters had any autoimmune disease, compared to 1.6% of unexposed women. The only condition occurring substantially more often in DES Daughters was Hashimoto's thyroiditis. Graves' disease, pernicious anemia and rheumatoid arthritis were somewhat more common, but possibly due to chance.

Observational studies cannot

show that an exposure caused a condition, but it's more likely if the condition is worse or more common with higher doses. In the 1988 study, 3.7% of women with DES-caused vaginal tissue changes had autoimmune disease, compared to 2.5% of DES Daughters without those changes. That finding could have been due to chance but suggested possible DES involvement.


Several studies since then have not had firm conclusions. A very small 2001 study (26 women) found that T cells—immune cells that identify and/or kill pathogens—behaved differently in DES Daughters compared to unexposed women.

Then in 1996, Dr. Arthur Herbst—the physician who first identified the increased risk of clear cell adenocarcinoma in DES Daughters—compared autoimmune disorders among children born to DES mothers in a 1950s randomized controlled trial for DES exposure. No increased risk of autoimmune disease showed up, but the population (549 DES-exposed, 487 unexposed) may

have been too small to find a link. A 1998 study found increased risk for immune-related infectious disease—specifically bladder infections and measles—in those exposed to DES, but no increased risk for autoimmune disorders.

In 2010, a study led by Rebecca Troisi found no increased risk for lupus, optic neuritis or idiopathic thrombocytopenic purpura in medical records. (Most earlier studies used participants' reports instead of medical records.)

But that study found rheumatoid arthritis risk was five times higher in DES Daughters under 45 years old—yet 90% less likely in women older than 45. Numbers in that study were also possibly too small for reliable conclusions, but no follow-up study has been published.

So, no specific, individual autoimmune conditions have been consistently linked to DES, but too few studies exist to rule it. It's biologically possible, and at least one study suggests age-related risk for rheumatoid arthritis. The answer will remain uncertain until more studies examine autoimmune disease. 

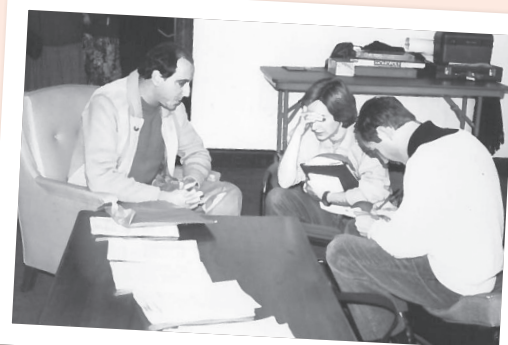


# DES Action: The Early Days

*Enjoy this selection of photographs we culled from the archives of DES Action USA. These photos are from the 1980s. In the Summer issue we'll have photos from the 1990s. If you see any photos mislabeled, please send us corrections!*



May 1988 board meeting and 10th Anniversary dinner: (L-R) Joyce Bichler, Mo Rafael, Andrea Goldstein, Joan Emery, Libby Saks, Kathy Bella, Naima Major, Shirley Simand, Kari Christianson, Nancy Adess, Pat Cody



Michael Freilick (other person unknown), 1988 Annual Meeting



Joyce Bichler and Dolores Wallgren, October 1981 Annual Meeting



Ellen 'T' Hoen, Anne Levadou (?), Oct. 1988 Annual Meeting



Sidney Wolfe, MD, Public Citizen, October 1989 Annual Meeting



October 1989: (L-R) Dr. Kenneth Noller, Mayo Clinic, Panel: Andrea Goldstein, Deborah Wingard, Pat Cody



DES Action USA members in a Workshop, Oct. 1988 Annual Meeting. The woman at the center of the photo taking notes was from the Massachusetts Dept of Health, not a DES Action member.



Linda Martin, DES Member, 1981 Annual Meeting



Sherry Whitmore, October 1981 Annual Meeting



Fay Sabe, October 1981 Annual Meeting

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## Join Us For Our Facebook Live Interviews

As part of our 40th Anniversary celebration, we've been interviewing leaders in the DES community. If you can't watch live, you can see the archived videos in the Members Area of the website.

### Coming Up



**May 18, 4pm  
ET: Jacquelyne  
Luce, Ph.D.**

Visiting Lecturer  
in Gender Studies  
at Mount Holyoke

College and principal investigator of a new research project, "Embodying Transgenerational Exposure: Gender/Sex/Sexuality and Experiences of Being DES-Exposed." She'll update us on her interviews with members of the DES-exposed population regarding gender.



**June 21, 7pm ET:  
Dr. Nita Karnik  
Lee** specializes in  
the diagnosis and  
treatment of women  
with gynecologic

malignancies including clear cell adenocarcinoma. Her focus is on providing comprehensive and compassionate care to women diagnosed with ovarian, uterine, cervical, vulvar or vaginal cancers.

If you haven't watched the previous videos yet, catch up with them in the Members Area:

In April, DES Action USA Executive Director Su Robotti interviewed DES lawyer Michael London (photo top right) about the current state of lawsuits and what kinds of actions are still possible.

In March, Su interviewed Susan Bell, author of the book, *DES*



*Daughters: Embodied Knowledge, and the Transformation of Women's Health Politics in the Late Twentieth Century.*

In February 2018, Su interviewed DES Daughter and Peabody Award-winning documentarian Judith Helfand about her movie *A Healthy Baby Girl*.

In January, Su talked with Dave Fuehrer, creator of the StupidCancer app. Dave's team added DES-exposed as one of the communities on the free app (available for iPhone now, Android soon).