

# No Increased Risk of Cancer in DES Sons

DES Sons do not appear to have an increased risk of any type of cancer compared to men of the same age who were not exposed to DES in utero, according to a new study. The research, funded by the National Institutes of Health, was published July 16, 2021 in the journal *Cancer Epidemiology, Biomarkers & Prevention* (doi: 10.1158/1055-9965.EPI-21-0234).

The study relied on data from the *DES Combined Cohorts Follow-up Study* of 4,101 men born between 1953 and 1994, including 2,001 who were exposed to DES in the womb and 2,100 who were not exposed. Findings arose from combining four unrelated previous study groups of sons born to women in studies related to DES.

The men from three of these groups had responded to questionnaires about every five years between 1994 and 2016, including questions about any history of cancer. The total number of men who filled out questionnaires during the full study period included 990 DES Sons and 998 unexposed men.

A total of 393 cancer cases occurred across both groups, including 187 cases in the DES Sons group and 206 cases in the unexposed group. Although the cancer cases were reported by the men, the researchers also gathered medical records to confirm the diagnosis for as many cases as they could.

Researchers were able to get the records for about 85% of the men who reported having cancer

between 1994 and 2011, and nearly all the medical records (95%) confirmed the diagnosis. Since the accuracy was so high, the researchers did not verify any later reports of cancer. But the researchers did check cancer registries to find any additional cases of cancer or any deaths from cancer in case some were not reported.

When calculating risks for prostate cancer, the researchers adjusted their analysis to take into account the participants' ages. Even though race and family history are also risk factors for prostate cancer, the study involved nearly all white participants, and the family history

was the same in both the DES-exposed and unexposed groups.

Other factors that were similar between the groups included those who had vasectomies and histories of smoking and alcohol use. DES Sons were a little more likely to get screened for prostate cancer than unexposed men, but the difference was small.

Even though some animal studies have suggested that prenatal exposure to estrogen can increase the risk of prostate cancer, the researchers did not find an increased risk of prostate cancer in DES Sons, even in those with obesity.

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## DES Lawsuits: Answers to Your Most Common Questions

Some of the most common types of questions we receive at DES Action are questions about pursuing lawsuits against the pharmaceutical companies that manufactured DES.

DES Daughters have filed thousands of suits since the damage of DES exposure became public in the 1970s, according to Michael London, a lawyer at the firm Douglas & London in New York who has handled many DES cases over the years, and the cases haven't stopped.

It's impossible to know how many active suits there are today,

but it is still possible to file a suit if the statute of limitations for your injury has not passed. (More on that below.) When people call to ask whether their particular situation can make a "good case," however, that's not a question we can answer. Every case needs to be assessed by a lawyer to determine whether it has a chance of being successful.

"The range of injuries and the ranges of exposures and causation patterns are sufficiently wide that you can't make generalizations about what's a good case and what's

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## Website Login Troubles?

Remember what email you used to join DES Action! Some members have experienced login problems using an alternate email address by mistake.

If you try to log in with a different email, it will create a duplicate record without your giving history or any notes, like communication preferences.

If you have any problem, or if your email or any of your contact information has changed, or you've forgotten your username and/or password, please contact Community Manager Britt at [britt@desaction.org](mailto:britt@desaction.org) on Mondays, Tuesdays and Thursdays.

## DES in Medical School Curricula

We regularly get the question about whether DES is still taught in medical school or why young doctors don't seem to have learned about it. We have looked into whether it's possible to lobby for the inclusion of DES curriculum in medical schools, but there is no governing body that controls curricula across all the states' schools. Each

medical school determines its own curriculum. There is an organization called the American Association of Medical Colleges, but this body does not have direction over the specifics of medical school curricula. If we learn of a way that we can push to ensure more instruction about DES is included in medical schools, we will pursue it.

## DES Awareness

Suzanne Robotti, DES Action's executive director, wrote an article about December 2020's Beyond Genes conference in the journal *Biology of Reproduction* (DOI: 10.1093/biolre/ioab146).

Her article, "The Heritable Legacy of Diethylstilbestrol: A Bellwether for Endocrine Disruption in Humans," was another opportunity for DES Action to raise awareness about the legacy of prenatal DES exposure and ensure that the research and medical community know of the millions of people still living with the health effects of this drug.

To read the article, please visit the Member Area on [www.desaction.org](http://www.desaction.org) and scroll down to "Beyond Genes: The Online Conference On Non-Genetic Inheritance In Human Disease."

## Renew Your Membership

It's easier than ever to renew your membership. Just log into the site using the email you registered with and your password. If you don't remember your password, you can reset it.

If you no longer use the email you signed up with, send your new address to Britt Vickstrom at [britt@desaction.org](mailto:britt@desaction.org). She will set a temporary password for you.

Thank you for supporting DES Action USA with your membership.



## MISSION STATEMENT

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

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not a good case,” said Roman Silberfeld, an attorney who has handled more than 50 DES cases starting in the 1970s. “Each one is deserving of its own fair, specific and impartial evaluation by somebody who knows what they’re doing.”

With that said, we’ve done our best to answer several of the most common questions we receive related to filing lawsuits for DES-caused damage. Remember that we have several legal resources available on our website at [desaction.org](http://desaction.org).

We’ll be addressing more questions in the next issue of the VOICE, so if you have a question we haven’t addressed or information that may be helpful to members, please let us know. Some of the issues we’ll address in the next issue will be Third Generation lawsuits, what to do if you only recently learned about your DES exposure but have an older injury, and how long cases take.

Do you have an active DES case? We’d love to hear from you if you’re willing to discuss your case. Please email Tara at [tara@desaction.org](mailto:tara@desaction.org) to let us know.

### **What is the statute of limitations on lawsuits?**

The statute of limitations varies according to the state you live in, but they all begin when you first discover the injury, such as a cancer diagnosis or another condition that develops. The statute of limitations in Minnesota, for example, is six years, but in California, it’s two years, according to Silberfeld. “Some states are more liberal on what triggers the clock to start ticking,” he said.

### **What kind of documentation is necessary to start a lawsuit?**

When it comes to the actual paperwork you need, “the real battlegrounds are exposure and causation,”

Silberfeld said. Causation is based on your medical records showing proof of your injury and a medical expert who will testify with reasonable medical certainty that your injury was caused by DES exposure.

The gold standard for exposure is your mother’s medical records. If your mother is still alive and can recall receiving DES, that can be successful in many cases as well.

If neither of those are possible, another option is to show that your mother had a history of miscarriages, which provides “an inference that the drug may have been given,” Silberfeld said.

It may also be possible to prove exposure through the injury itself for a couple of conditions that are almost exclusively linked to DES, such as a T-shaped uterus clear cell adenocarcinoma (CCA), a type of vaginal/cervical cancer.

If your injury is cancer and you have a family history of cancer, you should be prepared for the defendant to argue that your cancer was a result of family history instead of DES exposure, so a medical expert is needed to counter that claim.

In New York and several other states, there is no need to prove who manufactured the DES. However, knowing the manufacturer helps to prove your exposure. To identify which manufacturer made the specific DES formulation your mother received, a prescription slip is the best evidence. It should be possible to still get these records for mothers who were in the military or dependents of a serviceman. Some pharmaceutical associations also have archived records.

Without a prescription slip, there may be other ways to show proof of manufacturer, such as identifying the pharmacy providing the drug and showing that the pharmacy only carried DES from a specific manufacturer.

For example, in one successful case litigated by attorney Ron Ben-

jamin, he canvassed all pharmacies in a 40-mile radius and established that Lilly pharmaceutical representatives had agreements with those pharmacies to use Lilly products if the person requested a generic. Those agreements successfully convinced the jury that the plaintiff’s mother was more likely than not to have received a Lilly pill.

If you don’t have a way to prove who the manufacturer is, you may be able to recover damages from all the companies, with each paying a proportion of the total damages based on their total market share the year your mother was pregnant.

This market share option is only available in some states, however. If you’re suing in a state that does not recognize market-share payments, you must prove who the manufacturer of your mother’s drug was to recover damages. Further, if the manufacturer is no longer in business, you won’t be able to recover damages.

### **Has there ever been or is there a current DES class action lawsuit?**

A class action suit cannot be brought against pharmaceutical companies for DES damage because the damage varies too much by individual. For a class action suit to be brought, the harm needs to be similar across a large group of individuals. Many class action suits, for example, include companies that have overcharged customers by the same amount.

With DES, the harms can vary greatly from one woman’s experience to another’s, which makes a class action suit not legally possible, so there is not and has not ever been a class action suit related to DES effects. However, some judges have, at their own discretion, rolled together similar cases, which has caused some confusion among those who thought they heard about a class action suit.

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# Denise Shares Her Story

My DES story actually began before I was told that I had been exposed in utero. In elementary school, I experienced multiple bladder infections that led to my mother's gynecologist stretching my urethra when I was 8 years old without an anesthetic, since my father was opposed to anesthesia for a child my age.

You can imagine the pain, which was exacerbated when my mother got really mad at me during the procedure and said that I was embarrassing her. I gritted my teeth and wept silently through what I equate to rape. Needless to say, I have only complained once of a bladder infection since.

As a young adult, my periods were unbearably heavy and full of discomfort. I was told to tough it out. I remember in fourth grade, I had not told my parents that I had

into my skin and hurt.

At the age of 15 my mother told me that I had been exposed to a drug in utero called DES to prevent her from losing me while she was pregnant with me.

She said that after she had had my sister, four years before me, she had lost three babies. Her doctor, a family friend, had said he could help her carry me to full term by giving her diethylstilbestrol.

The doctor gave my mom two doses of DES before my father, a veterinarian, learned about it. When he found out that she had been given diethylstilbestrol, my father asked the doctor how much she had received. The answer sent my father into a rage.

"That is more than I would give a cow to fatten him up for slaughter! Do not give my wife any more

tive anatomy felt like another violation. The doctor did not speak or make eye contact. The exam became another opportunity for me to perfect my ability to disconnect from my body, as I felt violated. I felt he didn't think much of my parents' claims about DES exposure, even though he had the records showing I had been exposed. The exam did not reveal any obvious signs of DES exposure, such as a T-shaped or tilted uterus. He said everything was normal.

I got pap smears then and every year after that at my mother's insistence.

When I was 25, my pap smear came back with abnormal cells. I didn't know the doctor, but he looked at me like I was a whore. He asked if I was sexually active, and I said yes, that I had had one boyfriend. He said it didn't matter how many boyfriends I had had—what mattered was how many girls my boyfriend had slept with.

I walked out of his office with my head hung down and vowed to not return, and I didn't receive any follow-up regarding my abnormal test results. Meanwhile, I met and fell in love with the love of my life, an officer in the Coast Guard. A quick romance led to an engagement, but a pap smear in a Navy hospital spelled trouble. I underwent five biopsies with no anesthetic, and they found precancerous cells. The staff told me they needed to remove part of my cervix immediately.

They also asked why I never went back to my previous doctor, telling me this could have been prevented. The Navy doctors performed a cone biopsy—a quarter-sized slice taken from my cervix—and I was told I was good to go and that I would be fine.

However, it turned out I wasn't fine. After eight years of trying to get pregnant, five laparoscopic

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started my period, and I resourcefully stuffed my underwear with toilet paper and went about my business. After the bladder stretching, I'd be damned if I was going to share any of that with anyone!

I remember being called to the school cafeteria to meet with someone, and when I stood up, there was a large pool of blood on the bench. That night my mother angrily asked me why I hadn't told her that I had started my period. I said nothing and was given an elastic belt to attach pads to, and that was that, except that the belt cut

of that drug," he said. "If she loses the baby, it's nature's way." She wasn't given any more doses after the two she had received.

Then my mother told me that I would have to immediately be examined by a specialist. I had no idea what any of that meant or what would happen during an examination, because I was not sexually active or aware of anything going on down there, other than my extremely long and heavy periods. I had disassociated myself from my body when my urethra was stretched.

The exam checking my reproduc-

surgeries to remove extensive endometriosis, and two artificial inseminations, we conceived!

I was thrilled. Finally, I was pregnant and I felt great—except for an unbelievable pain in my crotch that felt like the baby was going to fall out. At five months, my wonderful OBGYN sewed my cervix shut. But at 28 weeks, my water broke and I was sent to the maternity ward in my small town and kept on bed rest to avoid starting contractions and infection.

On the third day, contractions started, and an ambulance took me to a hospital with a good neonatal department. But when I arrived, all the maternity rooms were full, and I was put in a dark storage closet with three other women on gurneys with shower curtains separating us.

Someone came in the middle of the night to give me a shot of something, and I asked her what the shot was for. She left, came back, and said, "You were right, this isn't for you." I learned at that point that I had to advocate for myself.

The next day I got a labor room, but after I had been in labor for 22 hours, someone realized my stitches hadn't been removed even though I had told them about the stitches when I arrived at the hospital and again in the labor room.

They wheeled me into a tiny closet-sized room where an intern tried to remove the stitches, again with no anesthetic. It was unbearable because the stitches were embedded into what was left of my cervix, and the doctor worked for over an hour while I continued having contractions. He was finally able to get them out.

After a few more hours of labor, the doctors discovered I had an infection and needed an emergency C section. Everything was a blur. I was told my baby girl was fine but that she needed to go to the neonatal center. Five bags of high potency antibiotics were pumped into me. With the fifth bag, I started having an allergic reaction. Ultimately,

though, we had a beautiful baby girl at 4 lbs 15 oz, and we took her home a week and a half later.

A year later, I was pregnant and on bed rest again when my water broke at 28 weeks. This time, I was immediately sent down to a hospital with a high-risk neonatal unit, where I received a private room and stayed for three weeks, taking magnesium to prevent contractions. One morning I noticed green mucus in the toilet and showed the nurse. She said it was nothing—probably my membrane plug, not to worry—and flushed the toilet.

By one o'clock, I had spiked a fever and the baby was stressed, so we had to do an emergency C section. I gave birth to a beautiful blonde baby boy who was whisked off to neonatal intensive care. I never saw him again.

My husband stayed with him and periodically returned to give me updates. I was loaded up with antibiotics, making me itchy, and felt awful because my whole body was infected. In less than 24 hours, I was told my son had died from a streptococcus infection.

Words cannot express the dark tunnel I went down for several years—the anger, rage and injustice of it all and the continual abuse inflicted on my body.

A little over a year later, I had an emergency appendectomy—a procedure no one in my family had ever had—and then experienced unbearable pain from fibroids. Despite the pain, I still wanted another baby because I didn't want my daughter to be an only child. My husband didn't want to go through it again.

I did get pregnant again, and my membranes ruptured at 24 weeks. I remained on bed rest in the local hospital for two weeks before contractions started and I delivered a baby that would not survive. My husband left me alone during labor, and I had a vaginal birth myself. I felt my baby kick his way out, but I was told he passed.

Then I felt a warmth running

down my back. I was bleeding out. I saw my husband in the corner talking to the doctor, and he looked like he was in shock. The edges of my vision began blurring, and all I remember is the hospital staff running me down the hallway fast. It was not until the next day that I

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held my dead baby and cried loud, mournful, soul-wrenching sobs.

At home, I ate liver to build up my strength. My OBGYN hadn't given me a blood transfusion because he was worried about AIDS (it was 1994), even though technically I needed one. He told me to eat a lot of meat. I healed, gathered my strength, and loved my daughter with every ounce of strength I had.

Two years later, I demanded a radical hysterectomy. I was tired of fibroid pain, endometriosis, and quite frankly, of sitting around waiting for cancer. Another specialist did the procedure, reluctantly. My OBGYN got the pathology results and told me it was obvious to him that my uterus was abnormal, about the size of a walnut instead of a fist. He believed it was from my DES exposure. I thought, “There! PROOF! Now I can rest.”

For several years I enjoyed having no periods or pain. I rebuilt my self-esteem, became the best teacher my school district had ever seen and then became a ball-busting lead negotiator in my position with the teacher's union. I channeled every ounce of my love into my teaching and daughter, and every ounce of my rage and anger into negotiating for better working conditions for my

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## Denise Shares Her Story

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colleagues.

Ten years after the hysterectomy, my bladder began acting up. I had excruciating, immobilizing pain that kept me from doing my job. I would literally be frozen in my chair, unable to stand, while I released my students for recess.

I saw a specialist and learned I had interstitial cystitis, a chronic condition that causes bladder pressure and pain. For two years, I endured weekly treatments while I experienced worsening pain. I underwent a full year of physical therapy for pelvic floor pain and the interstitial cystitis, separate from the years of mental health therapy I had needed by now.

That brings me to today in 2021. I wanted to share all this with you because life has come full circle a bit.

My daughter recently gave birth to a beautiful baby boy 17 days ear-

ly. He's fine and thriving. But why was he early? It was her first child. Aren't they supposed to come two weeks late?

Twelve hours after her water broke, she had not begun contractions, so they induced her. He was born 12 hours later at 6 lbs., 15 oz. and 19.5" long—the exact length my daughter and son had been when they came into the world at 7 months.

A connection? I think so! Do I want to alarm my daughter? No. I want to love and hold my grandson. I want to live a full, pain-free life. I want to flush DES down the toilet. But I can't. I can't pretend that it hasn't influenced my very being. I can't pretend that every time I hear that acronym I don't feel sick. I want to help others understand.

I am grateful for DES Action. The organization's information and support is critical to humanity. Doctors and drug companies don't have the right to experiment with

our bodies.

I do, however, believe in science. I believe my father saved my life in many ways. His background and knowledge of the drug stopped what could have been an even worse outcome for me. I love both of my parents regardless of the things that happened. They both were doing their best, just as I was doing my best to build a family.

My hope for the future is that all doctors will know of the plight of DES survivors and be willing to do the work and research to help us live our lives to the fullest and to never allow this to happen again. I hope my story helps someone in some small way.

I check DES Action's website because I choose to live my life without fear. The website grounds me, scares me, comforts me and reminds me of who I am and what I need to do to advocate for myself, my daughter, and all other DES survivors.



## DES Lawsuits: Answers to Your Most Common Questions

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### How do I find an attorney if I want to bring a suit?

The DES website includes a list of attorneys who have litigated past DES lawsuits. If one of these attorneys is not available or close to you, ask them for a recommendation in your state.

If they aren't able to help, contact your state's bar association and ask for help identifying a personal injury lawyer who has handled pharmaceutical-exposure lawsuits.

"It's always best to start with a lawyer who's close to your home," Silberfeld said. "You want to have ready access to your lawyer as the client, and the client needs to be available to the lawyer as well."

That said, you can use lawyers who are out of state. It's more important to have an attorney experienced in handling DES cases than a lawyer

who is in your state, said Benjamin.

"To the extent that people are thinking about legal recourse as a result of something that has happened to them, the most important bit of advice that I give everybody is take great care in choosing a lawyer in the same way you'd take great care in choosing a doctor," Silberfeld said.

"That's important because in law, everything is so specialized and even sub-specialized. There are product liability experts, then there are medical device experts and then there are pharmaceutical experts."

Silberfeld noted that there's an inner circle of the most competent people who do this work, and anyone considering legal recourse should choose a lawyer from that inner circle.

You can often find those people by contacting plaintiff lawyer associations or local chapters of the American Board of Trial Advocates or the

American College of Trial Lawyers. The most important question you can ask a potential attorney is, "Have you ever done this before?"

### What state do I sue in if I live in a different state than where I was born?

You can file your case from any state, but the state laws most likely to apply to your case will usually be the laws of the state where you were born, Michael London said.

It may be that a different state other than the one in which you were born has laws more supportive of your DES claim and proofs. In that case, you may be able to sue in a different state than where you live or where you were born, but you need to be able to justify why you're suing in that state, such as a state where the exposure occurred (even if you weren't born there), or a state where you lived a long period before your current state.



## **No Increased Risk of Cancer in DES Sons** *continued from page 1*

The researchers also did not find an increased risk of overall cancer in DES Sons compared to the unexposed group. Rates of cancer in both groups—DES Sons and unexposed—were slightly higher than in the general population, but the difference was small and statistically could have been due to chance.

The study did, however, uncover a surprising finding about urinary tract cancer incidence. DES Sons were about half as likely as unexposed men to develop urinary tract cancers. These include kidney or bladder cancer. The researchers were unable to explain why that finding might have occurred.

There were not enough cases of

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**“Even though the study did not find evidence of increased cancer among DES Sons, the researchers acknowledged that the question is not settled. The study did not have a high number of overall participants or cancers, so it cannot provide a definitive answer about whether prenatal DES exposure increases cancer risk in men.”**

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testicular cancer to determine if the risk was higher, lower, or not different between the groups.

Even though the study did not find evidence of increased cancer among DES Sons, the researchers acknowledged that the question is not settled. The study did not have a high number of overall participants or cancers, so it cannot provide a definitive answer about

whether prenatal DES exposure increases cancer risk in men.

Either way, however, the study at least offers some reassurance, the authors wrote, that prenatal DES does not contribute to a substantial increased risk of cancer in DES Sons. If any link to cancer does exist, it would almost certainly have to be small to not show up in this study.



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## **Did DES Cause Adrenal Problems?** *continued from page 8*

cholesterol were preventing the glands from producing a normal amount of steroids in the body. Inadequate steroid production can cause other problems in the endocrine system, including reproductive problems.

The same researchers published another study a year later that attempted to understand how DES interfered with adrenal glands' production of steroid hormones (DOI: 10.1530/JOE-13-0460). In rats, it appeared that DES reduced the liver's ability to produce a protein called Apolipoprotein E, which plays a role in metabolizing fat. Suppression of that protein causes a decrease in cholesterol in the blood, which appears to stunt the adrenal gland's steroid production.

Another study on rats several years later tried to learn how DES causes effects in the body using some part of the system linking the hypothalamus, pituitary gland and adrenal glands. But the main mechanisms they found were only

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**“As is true with so many other conditions, this lack of research findings does not mean we can completely rule out any effect on adrenal functioning from prenatal DES exposure.”**

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in the hypothalamus and pituitary gland (DOI: 10.1111/jne.12769).

What does this mean for those who were exposed to DES in utero? It's not really possible to draw any conclusions. There are only a couple of studies, and they were done only on rats. Not all animal research translates to human research, and the studies looked at effects on an adult rat receiving DES, not on offspring exposed during pregnancy.

The only type of research that could help us understand whether DES Sons or Daughters have experienced adrenal problems as a

result of DES exposure is to find higher rates of adrenal disease or adrenal insufficiency in observational studies. So far, we haven't been able to find any studies that identified a higher rate of adrenal insufficiency or adrenal conditions in DES Daughters or Sons than what is seen in the general population.

As is true with so many other conditions, this lack of research findings does not mean we can completely rule out any effect on adrenal functioning from prenatal DES exposure. That's especially true since the adrenal glands are part of the endocrine system, and there's a great deal scientists still don't know about the complexities of the endocrine system's functioning.

If there is any effect, however, it's small enough that it's not showing up as a cause of adrenal disease in more DES-affected people than unexposed people, or it's too rare to be able to detect the impact without much larger groups of DES-exposed and unexposed people to compare. -TH





# VOICE

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## Did DES Cause Adrenal Problems?

Since DES is an endocrine-disrupting chemical, one of the most logical places to look for possible DES effects is in the endocrine system. This is the body system that produces and regulates hormones, which then regulate metabolism and other essential bodily functions.

We have been asked recently whether any research has identified effects from DES on the adrenal glands. These glands sit on top of both kidneys and produce hormones to regulate blood pressure, metabolism, stress responses, the immune system and other processes.

There are several types of adrenal diseases. For example, Cushing's syndrome is a condi-

tion where the glands produce too much cortisol, a stress hormone. A different adrenal condition causes the glands to produce too much adrenaline. Another condition may lead the glands to produce too much aldosterone, a hormone that helps the kidneys absorb sodium and therefore helps the body regulate its water and salt balance.

So, what does the medical research say about DES and adrenal glands? Unfortunately, not much. The only research that directly addresses adrenal function and possible DES effects on it was done on rats.

One of those studies, from 2014, treated rats with DES every two days for two weeks

(DOI: 10.1530/JOE-13-0460). They then found that the DES built up in the liver, adrenal glands and pituitary gland compared to other places in the body.

The rats also developed enlarged adrenal glands that were heavier than normal and produced smaller-than-normal fat droplets. After a week of DES treatment, steroid levels in the blood and adrenal glands had decreased despite no changes to the adrenal tissue.

The researchers also found lower levels of the chemicals needed to produce steroids, especially cholesterol. They concluded that insufficient levels of

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