DES Action® VOICE

We identify, educate, empower and advocate for DES-exposed individuals

Inside

A Focus on Diethylstilbestrol

SUMMER 2019 #161

Makena for Preterm Birth

Safe and effective or echoes of DES?

Nearly half a million babies are born preterm each year in the United States, which has the worst rate of preterm birth among developed countries (and even many developing countries). Though the rate dropped from more than 12% a decade ago to just under 10% in 2017, it has started to tick up again. Given the lifetime risks of being born weeks or months early, doctors are anxious to find ways to reduce the risk.

But recent data suggests Makena, a progesterone-based drug used for over a decade to reduce preterm birth, may not lower the risk at all. (Generic versions of Makena, made of 17-alpha-hydroxyprogesterone caproate, are available, but this article continues to use Makena for ease of discussion.)

In March 2019, the company that manufactures Makena, AMAG Pharmaceuticals, announced the results of its most recent long-term trial for the drug. The study involved about 1,700 women and showed no decreased rate of preterm birth in women who took Makena.

Fortunately, it also did not show an increased risk of complications, but some doctors have questioned whether enough research exists on long-term risks to continue recommending a drug that may not work as well as believed.

To better understand the evidence base for using Makena or other progesterone drugs to prevent preterm birth, this author reviewed more than two dozen studies. The results are mixed, to say the least.

First, however, it's important to understand risk factors and existing treatments for risk of preterm birth, including the two hormonal drugs: vaginal progesterone, administered with capsules inserted into the vagina, and Makena, administered as a weekly intramuscular injection from 16 to 36 weeks gestation.

What are current recommendations to reduce preterm birth?

Treatments recommended to reduce risk of preterm birth depend on a woman's medical and social history and current pregnancy. Women at immediate risk of delivering a very preterm baby (before 34 weeks) may be prescribed tocolytics, a group of drugs that delay delivery up to two days.

This gives women time to take magnesium sulfate to reduce risk of cerebral palsy. Women may also be given corticosteroids anywhere from 23 to 36 weeks + 6 days gestation to speed up fetal lung, brain and digestive system development if early delivery is likely. But Makena and vaginal progesterone are aimed at preventing preterm birth in at-risk women long before delivery is imminent.

The biggest risk factors for preterm birth include a history of previous preterm labor or birth, pregnancy with multiples (twins, triplets, etc.), use of assisted reproductive technology to conceive (such as in vitro fertilization), conception within 6 months of a previous birth, an age under 18 or over 35, African-American race, a short cervix and prenatal DES exposure.

For DES Granddaughters, the most important advice is to have an in-depth conversation with their prenatal care provider.

But other health conditions, such as sexually transmitted or urinary tract infections, being underweight or overweight, placental abnormalities, gestational diabetes and high blood pressure, can also increase risk. Behavioral or social risk factors exist too, such as smoking or drinking alcohol during pregnancy, inadequate prenatal care, domestic violence, sustained high stress levels and exposure to pollutants in the environment, such as poor air quality.

Of all these risk factors, only women with a history of preterm birth are recommended to receive Makena. Research shows that Makena does not reduce preterm birth in women with multiples (twins, triplets, etc.), a short cervix or premature rupture of membranes, and the drug isn't

continued on page 6

About DES Action's Men's Discussion/Support Group

If you missed our last issue, you may not know about our DES Action Discussion/Support Group, moderated by Dan Rosenfield.

"I am beginning to understand many 'not quite right' things that went on in my body and mind as I grew up," said Dan, now 71. "And I am beginning to better comprehend and understand what's going on inside of my body and mind because I joined DES Action USA."

Sharing Our Experiences Privately

The idea behind the group comes from Dan's own experiences. "Over the years, and continuing today, a variety of symptoms have appeared that, only within the past year or so, appear almost certainly to be linked to my prenatal exposure to DES," he said. "I will tell you my experiences with them as we share our stories and advice in the private group. I, as your moderator, do not want to influence your identification of your own symptoms and feelings about them. We encourage you to communicate, candidly, information about your DES-triggered symptoms, from those you consider to be highly 'intimate' to those that are just annoying or so subtle as to be just a vague feeling."

This online discussion group is open to any DES-exposed men (Sons and Grandsons) who are current DES Action USA members. It is a private discussion/support group, and the information you discuss will not be shared beyond the group. If you know a DES Son or Grandson who might like to join the free men's group, have him email karen@desaction.org. She will complete the group membership for you.

amazonsmile

Did you know that when you buy something from Amazon, a few cents of your total can be donated to DES Action?

All you have to do is go to smile.amazon.com, and choose the nonprofit you'd like to help out.

Because DES Action is under the umbrella of MedShadow Foundation, you have to select MedShadow as your charity name, but rest assured all DES Action donations will go to the right place. Thanks!

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, email our Community Manager, Karen Calechman, at karen@desaction.org. She will set a temporary password for you.

Thank you for supporting DES Action USA with your membership.

Find us on Facebook

twitter

MISSION STATEMENT

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

Contacts

Sister Organizations

Australia

DES Action Australia, Inc.
PO Box 282
Camberwell 3124 Vic. Australia
info@desaction.org.au
www.desaction.org.au

DES Action NSW
14 Edmundson Close
Thornleigh NSW, 2120, Australia
C_devine@bigpond.net.au
www.desnsw.blogspot.com

France

Reseau DES France
1052 rue de la Ferme de Carboue
40000 Mont de Marsan, France
reseaudesfrance@wanadoo.fr
www.des-france.org/accueil/index.php

The Netherlands

DES Centrum
Postbox 1173
3860 BD Nijkerk
voorlichting@descentrum.nl
www.descentrum.nl

DES Action VOICE

Published quarterly by:

DES Action USA
178 Columbus Avenue #237182
New York, NY 10023

(800) DES-9288
(800) 337-9288
Email: info@desaction.org

Editorial Director and Social Media Manager..... Tara Haelle

Community Manager..... Karen Calechman

VOICE Production Manager....Deirdre Wyeth

MedShadow Foundation, Inc.
DES Action USA Group, LLC operates under the 501(c)3 status of MedShadow Foundation, Inc. DES Action is independent from any other organization.

MedShadow Foundation, Inc.

President .....Suzanne B. Robotti

Administration Manager.....Angela Smith

ISSN 1522-0389

New Evidence from Zebrafish on DES and Thyroid, Heart Effects

New research in zebrafish suggests a better understanding of how prenatal DES exposure might affect thyroid development and cardiovascular problems in humans. The study, led by Yi-Feng Li of Shanghai Ocean University in China, was published in January 2019 in the journal *Environment International*.

The study investigated how DES exposure affects the relationship between a developing thyroid and developing cardiovascular system in zebrafish. Zebrafish are a surprisingly helpful animal model for comparisons to human health because their genetic structure is similar to that of humans, yet their eggs are fertilized and develop outside the mother's body.

The researchers exposed zebrafish embryos to DES for 36 or 60 hours, starting 12 hours after fertilization. (They exposed a separate group of zebrafish embryos to another chemical called ioxynil, commonly used in pesticides and herbicides.)

Higher Heartbeat in the DES-Exposed

The zebrafish exposed to DES showed a heartbeat considerably higher than that of control zebrafish not exposed to DES. In fact, the increased heart rate of DES-exposed zebrafish was even higher than that observed in the zebrafish exposed to the other chemical, ioxynil, even though those fish also had a higher heart rate than unexposed fish.

Along with the higher heart rate, DES-exposed zebrafish had a lower volume of blood in the heart ventricle, differences in the shape of the ventricle, and a shorter aorta compared to fish not exposed to DES.

The researchers also found differences in the thyroid and genetic changes related to blood vessel and cardiovascular function in zebrafish exposed to DES. The cardiovascular system is instrumental in thyroid development, so negative cardiovascular effects from DES may then lead to thyroid damage.

Several other genetic or cellular pathways were significantly different in DES-exposed zebrafish, compared to the unexposed fish, including one related to type 1 diabetes.

The 'Disruptive Effect' of DES

"This study provides insight into the mechanisms by which DES and ioxynil affect zebrafish heart and vascular development and how these changes impinge on thyroid development," the researchers wrote. "The data obtained in the present study, together with our previous results, reveal a direct disruptive effect of ioxynil and DES on the heart and vascular development and an indirect effect on the thyroid."

The authors noted that recent research has suggested that DES Grandchildren have a higher risk of heart defects (see VOICE Summer 2017 for article), findings that match up with the cardiovascular results in this study and in the authors' previous research.

But the lack of evidence related to DES exposure and thyroid irregularities in humans makes it difficult to interpret the findings in this study when it comes to thyroid function or the relationship between the thyroid and the cardiovascular system. At the least, this study suggests there is a theoretical basis for thyroid problems in humans as a result of DES exposure.

This study's results suggest that prenatal DES exposure can affect blood flow in a vertebrate animal, though it's not clear how that might happen or whether it occurs in humans as well.

This study's findings are a step in the direction of understanding how DES might affect the cardiovascular system in general.

Given the existing research on cardiovascular risks in DES-exposed people, however, this study's findings are a step in the direction of understanding how DES might affect the cardiovascular system in general.

DES directly disrupts cardiovascular development, the researchers concluded, "and there is an associated disruption of thyroid tissue that most likely has long term consequences."

DOI: 10.1016/j.envint.2019.01.009

Editor's Note

Our Spring 2019 edition included the article about the Connecticut Chapter archives moving to Smith College. We were looking for the original founders of the Chapter. Laura Minor (who was highlighted in our Spring 2018 edition) reached out to us that she and Christine Witzel ran the original Chapter. Thank you for all you've done, Laura!

Q&A with Peggy Roth

Peggy Roth

An accomplished journalist, DES Daughter Peggy Roth learned many lessons about her health—and how to find the care she needed and deserved—the hard way. She shares insights from her journey.

Q: Tell us about learning of your exposure to DES.

A. I learned about my exposure to DES at UVA Student Health during a routine pelvic exam by the remarkably vigilant Dr. Peyton Taylor, who was then a resident and would later return to be chief of GYN oncology. It was my first pelvic exam ever.

I had gotten my first period the previous April, at age 17. During my high school years and probably before then, my parents were preoccupied with financial crises and had little to no money for medical care for them or me, the youngest of four kids and the only one still dependent on them.

Dr. Taylor saw that I had the classic cervical coxcomb of DES daughters. He advised me to ask my mom to request her medical records from her OB-GYN. The OB-GYN told her the records had been destroyed in an "office fire."

I had never heard of DES, so I asked Mom about it. She told me she had taken it throughout her pregnancy with me as a preventive measure after a miscarriage scare four years earlier, and during at least the last trimester of her pregnancy with my next-older sister.

Mom carried my sister to term without further difficulties and credited that to the DES and the care of her OB-GYN, whom she greatly admired. Not coincidentally, and unknown to my mom when I learned of my DES exposure, my sister was also born with a T-shaped uterus and was diagnosed in her 40s with a benign pituitary adenoma, a known effect of in utero DES exposure.

After learning of my exposure, I did some cursory research on DES but didn't let the details sink in. I had always known that I was a little different, a late bloomer at nearly everything physical but a quick learner and high achiever academically—so I was basically okay, right? My cloak of denial remained in place for many years to come, until I was facing a hysterectomy at age 48 due to messy cervical dysplasia.

Q: How has your DES exposure affected your life?

A. In a way, my cloak of denial had a silver lining in that I enjoyed my only pregnancy without a lot of worrying. The pregnancy did not come easily, however. At age 35, my husband and I had not been able to conceive, so my GP, who had a particular interest in OB-GYN, did a preliminary hormonal workup. Finding that I was hypothyroid, she prescribed supplemental thyroid medication and, because of the complexities of my DES exposure, she referred me to an infertility specialist.

During my infertility workup, I learned I had a T-shaped uterus. I went through about six months of testing and monitoring and was about to begin fertility injections when I got pregnant. I carried our son to full term; he's now 26 and thriving. After a rocky first week of life with jaundice, he's never exhibited any effects of my DES exposure or other health problems. He's our amazing one and only since we tried, without success, to conceive again when I neared 40.

Then, at 44, I started having difficulty swallowing. At times while swallowing, I felt nothing from the top of my neck down. I consulted a gastroenterologist treating me for hyperacidity, and he referred me to an ENT to rule out an obstruction.

The ENT found a mass at the back of my tongue that wasn't visible from physical examination. A CT scan confirmed her suspicion that the mass was ectopic thyroid tissue. Normally, the embryonic thyroid gland descends to the base of the neck between the third and seventh week of gestation. What I had, a lingual thyroid, means the thyroid fails to descend. It's rare, occurring in about one in 100,000 people.

While most patients are asymptomatic, the mass may enlarge and cause dysphagia, difficulty breathing or a sensation of choking.

Now I understood better why I was hypothyroid and probably why I was so little for so long; my thyroid hadn't had room to develop to normal size. But what had caused it? Was this DES… again?

There's no definitive linkage between ectopic thyroid and DES, possibly because no one appears to have looked for one. A Georgetown endocrinologist suggested a connection was theoretically plausible, given the known endocrine effects of DES exposure, but he cautioned that no linkage had been scientifically established.

This was my first glimpse of the long-term unknowns of DES exposure and an eye-opener to the disinterest with which most medical professionals regarded in utero DES exposure, 28 years after doctors stopped prescribing it to pregnant women.

I had a hysterectomy in 2004 after

my gynecologist, belatedly taking seriously my concerns about mid-cycle bleeding, found I had developed "moderate to severe" cervical dysplasia. Weary and leery of the surprise health issues possibly related to DES, I had my ovaries removed in 2007, when I was already in menopause, as a preventive measure after my endocrinologist observed that I had abnormal abdominal bloating. The ovaries showed no pathology, as it turned out.

I now can no longer pretend that I have no major concerns, whether related to my DES exposure or not. For the past 10 years, I have been living with neurological issues that began with a mild tremor in my left hand. I'm currently trying to figure out, with the help of a wonderful, dedicated, persistent neurologist, whether the tremor and associated symptoms are Parkinson's disease, as initially diagnosed, or something atypical, and how best to treat them.

Q: How has your exposure to DES affected your perceptions of the medical or pharmaceutical industries or government regulation of them?

A. In 2008, I delved deeper into my health concerns, thinking I was in a position, as a trained journalist with good insurance and job security, to find answers. Could there be more anomalies in my odd bod, waiting to be discovered? I just had to ask the right people the right questions and put the answers together.

Was I ever naive.

I learned from hundreds of visits in the past decade to multiple specialists that doctors generally don't like anomalies. Patients with rare anomalies a doctor hasn't seen can take valuable time to research and understand, often with no clear resolution.

Now I understood why I'd seen so much avoidance and even flat-out denial of symptoms I'd asked doctors about. Once, a top specialist charted "no tremor" when I saw him about my tremor. I showed him the report about the tremor from another medical center and showed him the tremor in action.

Unfortunately, that was one of many instances. I often found that if my symptoms did not show up on blood tests or imaging, many, if not most, doctors would go no further. It was up to me to figure out what to do next.

Finally, I found a multidisciplinary neurology practice that welcomes my concerns, observations and even anomalies. Although my neurologist naturally thinks and tests first in terms of conditions she's familiar with, she will not allow me to apologize for being a beyond-the-textbooks case and has shown every indication that she is committed to taking the steps necessary, within her scope of practice, to treat my impairment to the extent possible, even if the treatment is not obvious. She's quite the opposite of a couple of doctors who've commented to me, "Your file's awfully thick."

I am very lucky. Doctors don't have to go the distance for every patient who walks through their doors; at least they don't have to in our profit-oriented health care system. Perhaps if the system rewarded positive outcomes and patients' quality of life more than "efficiencies" of practice, there would be greater incentive for doctors to welcome patients with complex medical profiles, like DES offspring.

I wish we DES offspring had our own specialty in medicine. Having access to a multidisciplinary team well-versed in the workings and possible long-term effects of DES exposure would go a long way toward alleviating the illnesses and worries that we shoulder every day. I'm just one DES offspring, and I now need the expertise of neurologists, gynecologists, endocrinologists, pulmonologists, otolaryngologists, radiologists and internists to support my health care. Only in gynecologic oncology have I found skilled practitioners who are also DES-literate.

Q: Tell us about your experience with DES Action.

A. I found DES Action online when I learned I needed a hysterectomy. I was looking for a doctor I could trust to evaluate my cervical dysplasia and do any surgery necessary. In the process, I made a very dear friend, who introduced me to her terrific OB-GYN. He had seen her through a difficult pregnancy and performed my hysterectomy with excellent results.

I have since turned to DES Action as the best one-stop shop for historical information and resources on DES, to find other doctors and for the comfort of reading about other DES offspring and their experiences. I have not made nearly as much use as I could of DES Action's collective knowledge and experience, but I am relieved and happy to have the information and support DES Action has provided me.

Q: What is your hope for the future as a DES Daughter?

A. Three things come to mind: I'd really like to see a national DES Center of Excellence come to life, an organization that brings together experts and resources to track, study and presumably treat the long-term effects of DES exposure, in utero and otherwise.

Second, I don't want other DES offspring to waste the time I lost in pursuing health care from doctors who, it turned out, really didn't want to get involved. Every patient, but especially those with "difficult" conditions, should know how to find a doctor with the skills, interest and empathy to treat them properly, and then how to cultivate good communication with that doctor to achieve the very best health care available—including

continued on page 6

Q&A with Peggy Roth

continued from page 5

self-care, of course. Realizing that no one "owes" us relief is a difficult pill to swallow—I wish I'd realized this earlier!—but there are doctors out there who feel an obligation to heal and are committed to doing everything they can to bring their patients relief.

Finally, I don't want to end up being a write-off just because I'm a one-off. Having described my symptoms to many doctors over the years, I've gotten the sense that some specialists, even those at the top of their field, concluded that I couldn't be "fixed"—at least by them—but didn't want to tell me and risk denting their careers. But I can't let myself lose significant quality of life for lack of the right expertise. I have great faith in the collective knowledge, wisdom, ingenuity and motivation of American medicine to alleviate, if not heal, the most difficult of illnesses. I just have to keep knocking on the right doors.

You live, you learn. We're all living, learning and, perhaps most importantly, sharing what we've learned. It's a journey with a destination that I wish were more clear. Meanwhile, the most important advice I can offer people is to persist for the outcome you need. DES VOICE

Makena

continued from page 1

recommended for these women. Women with a history or risk of blood clots or breast cancer, uncontrolled hypertension or liver problems also may not be able to take Makena.

Vaginal progesterone—a different drug than Makena—appears to cut the risk of preterm birth nearly in half for women with short cervix though, again, it's not effective in women carrying multiples. The only non-drug option for women with a short cervix is cerclage, a procedure that binds together and reinforces the cervix, typically with sutures or synthetic tape. But cerclage is not recommended with multiples, when it can increase risk of preterm birth. (No current treatments exist to prevent preterm birth in multiples pregnancies.)

What are Makena's risks?

One concern noted in a recent *Wall Street Journal* article about Makena is an increased risk of gestational diabetes. But when researchers looked only at randomized controlled trials, in which two similar groups of pregnant women are randomly assigned to receive Makena or placebo, no increased risk of gestational diabetes appeared.

The handful of studies finding an increased risk were cohort studies—studies without a control group that can only use historical rates of gestational diabetes for comparison. This is not a reliable way to estimate risks since historical rates may be based on different populations with risk factors.

No other significant risks from Makena showed up in the research literature. A couple of studies found other benefits with Makena, such as increased birth weight, reduced complications or reduced newborn death. But these results only occurred in a few studies, sometimes with minor effects, so the evidence isn't strong enough to say Makena is responsible.

Not much long-term data exist on Makena's use during pregnancy, but researchers have learned a great deal since the disaster of DES. The body naturally produces extra progesterone during pregnancy. Based on today's understanding of women's reproductive systems, it's unlikely that added progesterone would have long-term effects on the fetus. Still, if the evidence for using it ends up being particularly weak, it's not worth even remote risks.

What's the bottom line?

The biggest limitation to studies of Makena is the diversity of study designs and populations. Some studies involve only women in the US while others include women only in Europe or elsewhere. Some have predominantly white participants while others have predominantly black participants. Some controlled adequately for other risk factors, such as smoking, while others didn't. Some studies were randomized controlled studies—the most reliable type—while others were single cohort studies without a control group.

Currently, it's difficult to say definitively whether Makena works effectively enough to prevent preterm birth in the small group of at-risk women recommended to receive it. Possibly it works in women with very specific characteristics that researchers haven't yet identified.

For DES Granddaughters or women in general at risk of preterm birth, the most important advice is to have an in-depth conversation with their prenatal care provider about options for their particular situation. A study discussed in the Winter 2019 VOICE, for example, found an increased risk of preterm birth in DES Granddaughters.

If your doctor recommends Makena, ask why and whether they've personally reviewed the most recent evidence. Ultimately, each woman must feel confident assessing the risks and benefits of the drug for her personal situation.

Editorial Note:

This article was reviewed by Kathleen Brookfield, M.D., Ph.D., M.P.H, assistant professor of obstetrics and gynecology in the OHSU School of Medicine. All decisions regarding the use of progesterone for preterm birth prevention represent the choices of a woman and her trusted health care provider, and do not reflect the opinions of Dr. Brookfield or OHSU. DES VOICE

Should Breast Implants Be Banned?

By Rachel Brummert

The FDA called a meeting of the General and Plastic Surgery Devices Committee to discuss and recommend action on breast implants. More than 80 women who suffered after receiving textured breast implants and expanders testified. The FDA GPSD Committee is composed of doctors and one patient representative, Rachel Brummert, founder and president of Patient Safety Impact and a contributor for Drugwatch. The committee was asked to determine the benefits versus risks of breast implants and their link to breast implant associated anaplastic large cell lymphoma (BIA-ALCL) and breast implant illness (BII). The following is an excerpt from a first-person account by Rachel Brummert, published on MedShadow.org. Go to that website for the full article. —eds.

Even before I saw the media cameras, I knew this hearing would be different from any panel I had already served on. As I took my seat on the panel, I watched as members of the media interviewed people in the hallway and the back of the packed room. It reminded me of when I testified at the FDA in 2015, on a medication safety panel about the adverse reactions I had to Levaquin. Only I was on the other side of it this time; I was a member of the advisory panel on a medical device panel. Being on both sides of the podium gives me a unique perspective about advisory panels, and I was certainly feeling the pressure. Clearly, a lot was riding on this.

After two days of testimony from more than 80 harmed women, breast implant manufacturers, access to medical studies and discussion among committee members, my concerns about guidelines and the information available to patients about breast implants and expanders are many. Based on scientific research provided to the panel committee and concerns from patients, it appears that women are getting sick from breast implants and even developing lymphoma from textured silicone gel implants. It is specific to only textured implants or expanders, and this raises concerns for me. Women who survive breast cancer and then opt for breast reconstruction are potentially signing up for a different kind of cancer—a man-made one. Because of this risk and based on scientific research, over 40 countries have banned textured silicone gel implants. The US has not taken any such action, and is instead finding ways to put a Band-Aid on a battle wound.

As consumer representative, I recommended that the FDA ban textured silicone implants because the lymphoma is specific to this particular type of implant, and I was met with swift pushback from my fellow committee members, all doctors.

Another issue that was raised was screening for silent ruptures. Currently the FDA recommends an MRI three years post-implant, and then every two years following. The FDA and the breast implant manufacturers cite noncompliance from patients as the reason for alternative screening options. MRIs are expensive and often not covered by insurance.

To lower the cost of follow-up, one member of the panel suggested mammograms as an alternative to MRI screening. I had to make sure I'd heard that correctly, because using mammograms for breast implant screening is, in my opinion, ridiculous. Mammograms are X-rays of the breasts. A technician will help you position each breast between the plates and the machine essentially squishes your breasts flat so it has a clear image. If you've ever had a mammogram, you know how necessary screenings are—but also how uncomfortable they are, even under the best possible conditions. Now imagine having breast implants. The panel likened breast implants to a water balloon, so I'll use their reference for context. Imagine a water balloon between two plates and squeezing it flat. It could rupture, right? The same goes for saline and silicone gel implants, which are prone to silent ruptures even without squeezing, through no fault of the women who have them implanted.

So the solution proposed by a physician on the panel was to use a machine that could cause rupture—in order to screen for rupture! If MRI screenings required a laboratory examination of samples of body tissue when seepage or ruptures are found, MRIs would be much more likely to be covered by insurance and women would be able to afford to comply with MRI screenings, thus taking a riskier procedure like a mammogram off the table.

I'm disappointed with how tone-deaf most of the panel was after two days of testimony from breast implant device makers and the 80+ people who came to speak about their harm. The advisory panel also discussed registries to track adverse events. The concern I raised was that there are several registries in existence with varying parameters. Because of their limited scope, data is incomplete. Case in point: Current registries only include new surgeries and reoperations and do not include breast implant illness. My suggestion to the panel was to create a centralized, universal registry where anyone can have access to the data—analysts, physicians and patients alike—and to make reporting mandatory. DES VOICE

DES Action® VOICE

DES Action USA
178 Columbus Avenue #237182
New York, NY 10023

www.desaction.org

Return Service Requested

It's easier than ever to renew your membership online. Visit www.desaction.org!

Does DES Cause Diabetes?

It possibly increases the risk

The most common effects from prenatal DES exposure tend to occur in the male or female reproductive system, including clear cell adenocarcinoma. But DES effects certainly extend to other systems in the body, particularly the endocrine system. Though less discussed, research does suggest a possible link between DES exposure and diabetes, but it's not a proven connection.

Research into endocrine disruptors in general has already found them to be associated with obesity and diabetes, particularly in animal studies. A 2010 research review of endocrine disruptors' effects, for example, discussed experiments in mice that found a quarter of those exposed to DES had higher blood glucose levels than unexposed mice (doi: 10.14310/horm.2002.1271).

Though animal studies cannot always directly translate to human studies, observational research suggests it is likely in the case of DES and diabetes. In a study of more than 8,000 men and women published in 2013, risk for diabetes was slightly higher in those exposed prenatally to DES, but the increase was not statistically significant, which means the small observed increase could be statistical chance (doi: 10.1097/eDe.0b013e318289bdf7). But the study could not necessarily rule out diabetes risk as a DES effect either.

Specifically among women, 4% of DES Daughters had diabetes compared to 3% of unexposed women, which was barely statistically significant. In men, DES Sons had a slightly lower risk of diabetes (5% vs. 6% unexposed), but the difference was not statistically significant in males. Still, the researchers concluded that risk of diabetes "may be greater in DES sons and daughters compared with those who were not exposed," but this study was unable to definitively show it given the size of the population and the small number of participants in the study with diabetes.

The bottom line? We can't say for sure that prenatal DES exposure definitely causes diabetes. However, there is enough animal and observational research to conclude that it's reasonably likely DES exposure could have enough of an impact on the endocrine system that it might contribute to increased diabetes risk. DES VOICE