DES Action® VOICE

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

Inside

A Focus on Diethylstilbestrol

WINTER 2022 #171

More Evidence Reveals Risks of Makena to Unborn Children

Prenatal exposure to the drug Makena has been linked to an increased risk of cancer, according to a newly published study in the *American Journal of Obstetrics and Gynecology*. The study's preliminary data was presented at the Endocrine Society's annual meeting in March 2021 before peer review. The new paper includes the complete study findings.

Makena, the brand name for the drug 17 alpha-hydroxyprogesterone caproate (17-OHPC), received preliminary FDA approval in 2011 to reduce the risk of preterm birth. Then in 2020, after studies showed no benefit from the drug, the FDA's Center for Drug Evaluation and Research proposed withdrawing it from the market, though it hasn't been withdrawn yet.

Before its 2011 approval, however, 17-OHPC was used decades ago after the FDA approved it in 1956 for various OBGYN conditions, including preventing miscarriage.

Researchers from the University of Texas Health Science Center in Houston, Texas, and the Public Health Institute in Berkeley, California, studied more than 18,000 pairs of mothers and their children, born between 1959 and 1966 in Northern California.

One percent of these children were exposed to 17-OHPC during pregnancy. Of those, most (70%) were exposed during the first trimester, and their mothers received an average of 2.4 injections total. Then the researchers examined cancer diagnoses in the women's children through 2019.

Children who had been exposed to 17-OHPC during the first trimester were 2.6 times more likely to develop cancer than unexposed children. In actual numbers, 1,008 of all children in the study were diagnosed with cancer, including 23 children exposed to 17-OHPC.

If exposed during the second or third trimester, males were still 2.6 times more likely to develop cancer later in life, but females were not. But since so few children were exposed only after the first trimester, there may not be enough participants to reliably estimate risk.

The researchers also found a higher risk of cancer with more injections. Children born to mothers who received 1-2 injections were 1.8 times more likely to develop cancer, but those whose mothers received three or more injections had triple the risk of cancer.

The researchers calculated the risk of cancer in exposed versus unexposed children after taking into

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More of Your Legal Questions Answered

In our last issue of the VOICE, we addressed many of the questions we've received from members related to suing pharmaceutical companies for damages caused by DES. Here are some additional questions and answers.

As always, we welcome your input regarding questions you may have about lawsuits related to DES or information that you believe the DES-affected community needs to know about this topic.

If I already received a settlement or damages payment in the past for a case related to one injury, such a T-shaped uterus, and then I develop another DES-related effect, such as CCA, can I sue again?

According to Michael London, a lawyer at the firm Douglas & London in New York who has handled many DES cases over the years, the answer largely depends on what you signed when you accepted the damages in the first suit, but most states have adopted a "two injury rule" or "second injury rule."

"If your second injury is held

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Endocrine Society Seeks to Continue DES Daughters Follow-up Study

DES Action has been continuing to communicate with the Endocrine Society regarding their support when it comes to continuing DES research. The Endocrine Society has a standing interest in the DES longitudinal (long-term) study, and its members appreciate how DES has been a clear demonstration of the harm associated with chemicals that interfere with the endocrine system, a spokesperson told DES Action.

Recognizing the importance of continuing the DES longitudinal study to better understand the intergenerational health effects of exposure to DES and other endocrine disruptors, the Society's Research Affairs Core Committee agreed to issue a meeting request to the National Cancer Institute leadership.

One of the meeting agenda items would focus on encouraging NCI to continue to support the study and seek opportunities to partner with other NIH institutes and centers to gather information and improve our understanding of potential health effects across the lifespan and multiple generations.

"The DES *Longitudinal Cohort* is an important human study that has had a powerful impact on biomedical research," said Dr. Laura Vandenberg, a member of the Society's Endocrine-Disrupting Chemicals Advisory Committee whose research focuses on endocrine-disrupting chemicals. "It is critical to continue this study so that we do not miss a unique opportunity to better understand the long-term effects of estrogenic endocrine disrupting chemicals on human health."

DES Action will continue to update members on any progress related to the continuation of the *DES Daughters Follow-Up* study.

-TH

Ask Your Doctor to List DES Action on Their Website and Websites Requested for the Doctor List

Does your medical professional's website include resources, such as ACOG, American Society for Colposcopy and Cervical Pathology, or NIH? Ask your doctor/medical professional to add our website www.desaction.org to their website. We'd also like to include doctor websites on our member-recommended Doctor List. Also, if your doctor/medical professional is no longer practicing or has moved, please let us know, so we can update the list.

- BV

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. She will set a temporary password for you.

Thank you for supporting DES Action USA with your membership.

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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 VIC 3124 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

The Netherlands

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

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DES Action USA
229 E. 85th St., Unit K
New York, New York 10028

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

Editorial Director and Social Media Manager.....Tara Haelle (-TH)

Community Manager...Britt Vickstrom (-BV)

Executive Director.....Suzanne B. Robotti

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President .....Suzanne B. Robotti

Administration Manager.....Angela Smith

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Member Q&A: Robert Pargament, a DES Son

Robert Pargament, a retired federal law enforcement officer living in Brooklyn, New York, found out he had been exposed to DES when he was 17 years old and just getting ready to leave for college. His mother told him she had been given the drug because of a previous miscarriage, but at the time he wasn't aware of any potential medical issues that could result.

In what ways do you know or suspect you have been affected by your DES exposure?

I was born with undescended testicles and at the age of 6 months had surgery for the repair of a bilateral hernia. In my mid-twenties, I had a case of epididymitis [inflammation of a sperm-carrying tube at the back of the testicle] that took a few months to diagnose.

Approximately 10 years later, I had symptoms of a second case of suspected epididymitis and went to a urologist for a follow-up. Further ultrasound resulted in suspected torsion of my right testicle. [Testicular torsion means the testicle rotates and twists the cord that delivers blood to the scrotum, thereby reducing blood flow and causing severe pain and swelling.]

I had surgery, and testicular cancer was discovered. Seminoma [a type of cancer that begins in germ cells in males] was the diagnosis, and they performed an orchiectomy [removal] of the right testicle, followed by radiation. Follow-up fertility testing revealed that I was not fertile and was unable to have children.

Since 1994, I have had negative tumor markers. During my 6-month post-op CT scan of my chest and abdomen—part of the standard post-cancer-treatment protocol—a possible mass was discovered on my thymus [an immune system organ in the front of the chest just below the clavicle]. Surgery revealed a benign thymolipoma [overgrowth of cells that does not cause cancer] that was removed. It was quite traumatic having your sternum opened surgically at age 37.

I have had low testosterone levels for the past 15 years, and recently, when my testosterone level was down to 25, I started weekly testosterone-replacement injections of Xyosted. [Editor's note: According to the American Urological Association, any testosterone levels below 300 nanograms per deciliter (ng/dL) is considered low.] My remaining testicle does not produce testosterone. I have been a Type 2 Diabetic since age 49. I have remained unmarried.

Can you describe what it's like to be a DES Son when so much of the research focuses on effects on DES Daughters?

I am concerned when I see issues of *DES Action VOICE* that do not have much or any information relevant to DES Sons. In 2001, DES Action volunteered my name to the CDC, which produced and distributed a manual for physicians that discussed self checks in DES Sons and possible complications of their DES exposure. I have not been included in any of the medical studies on DES Sons' exposure.

What issues do you feel continue to be the biggest gaps in DES research?

I have been diagnosed with anemia requiring iron infusions. The doctors have not been able to diagnose any blood loss or reasons for my low iron. Could it be related to my past radiation treatments? I would like to see a broader investigation into possible conditions that my DES exposure may have caused.

How did you find out about DES Action, and what led you to join?

When I had my testicular cancer, I was assigned overseas with U.S. Customs and was covered under the U.S. Department of State medical program. I received a phone call from one of their social workers and was sent pamphlets on testicular cancer and from DES Action.

In what ways has DES Action helped you personally?

I called the DES Action Sons Network coordinator, the late Mike Freilick, and his conversation was very reassuring to me. I contacted DES Action and became a member. Until Fran Howell's retirement, I would get an annual email from her on my birthday counting the years of me being cancer-free. DES Action may be a large organization, but we have a common issue, DES exposure.

What improvements would you recommend to DES Action?

There was a men's group that started, and I received a lot of email messages, but I don't feel that was a way to go to get DES Sons involved. Involvement needs to include exposure to all of DES Action. I would also like to see more studies with DES Sons.

What is your hope for the future based on your experience as a DES Son?

I feel that DES Action and the involved lawyers have been beneficial in stopping/restricting the use of DES. I hope to live a full life for many more years.

Editorial Note:
Q&A articles published in the VOICE represent only the opinions and experiences of the individual interviewed and do not necessarily represent opinions or positions held by DES Action or any scientific bodies.

What Do We Know About Effects of DES for Lactation Suppression?

Recent articles in the news about DES have led to questions and concerns about its use in the past as a lactation suppressant. At DES Action, we're always grateful to see DES getting attention in the media since, even all these years later, not enough people are aware of the DES disaster and how many lives it affected. At the same time, some articles do a poor job of putting discussion of DES in context when it comes to the scientific evidence about its effects.

When several articles reported on the fact that young mothers had been given DES to stop lactation after they were forced to give up their newborns for adoption, DES Action received a slew of questions. Here we've tried to address those questions with the information available.

What happened?

In both the United Kingdom and in Australia, young, unmarried women in the 1960s were forced to give their babies up for adoption after birth. Recent news articles have shared that some of these women were given DES, sometimes without consent or explanation, to suppress lactation.

These women were not informed of any possible risks from the drug, and doctors did not appear to have reliable information about risks. The women now seek restitution and recognition for the possible harms they were exposed to from taking the drug.

What do we know about the risk of cancer from being given DES for lactation suppression?

No studies we are aware of have investigated the long-term effects of receiving DES for lactation suppression. Several of the women who have shared their stories in the press noted that they were given multiple times the dosage recommended for lactation suppression.

At the same time, it's not clear what the usual dose was for lactation suppression or how it compares to the doses that DES Mothers received. A study from 1979 noted a dosage that seems likely to represent what a "usual dose" for lactation suppression would have been: 5 mg a day for a week, for a total dose of 105 mg.

Pregnant women given DES were typically prescribed 12.5 g during their entire pregnancy, which is 12,500 mg. That means the lactation-suppression dose described in the study is less than 1% of the dose given to pregnant women. Even if women received a dose three or four times larger than recommended for lactation suppression, they would still be receiving a much lower dose—under 5%—than what pregnant women received.

Research from the National Cancer Institute has found that DES Mothers have a 1.4 times greater risk of breast cancer, and a higher dose is linked to a higher risk of cancer. Given the low dose given to women for lactation suppression for a short period of time, it seems unlikely that it would have had much effect on breast cancer.

There is no evidence currently to suggest that adults who received DES have a higher risk of adenocarcinoma.

Will we ever get answers about the effects of receiving DES for lactation suppression?

Unfortunately, we probably won't. The time frame for being able to study this question would have been several decades ago, when it would have been necessary to identify women who received DES for lactation suppression and track them over the years, similar to the *DES Follow-Up* study.

At this point, there have been too many years of other exposures and life experiences that would make it too difficult to statistically separate out what kind of effects might be linked to DES exposure. It's also not clear how many women were given DES for lactation suppression, but it's not nearly as high as those who were given it to prevent miscarriages.

DES Action will continue to follow this story and report what we learn of any new developments.

-TH

GivingTuesday 2021

Thank you to everyone who donated to DES Action for GivingTuesday! Thanks to you, we met and exceeded our goal, and we can work on getting the member-recommended doctor search page updated!

Our goal was $2,500… and you gave $6,470.96! We had a total of 30 donors and gained a new member at the Patron Level ($200).

While a little over a third of the donors (37.9%) were already members, we received 62.1% of our donations from non-members.

As you know, DES Action relies on the generosity of its members to bring you membership benefits that include this quarterly newsletter, discussions groups with others in the DES-affected community, and access to a wealth of resources on our website.

Thank you again for helping us serve the DES-affected community.

Trial Finds No Benefit From Vaginal Laser Therapy

Women who received laser treatments for painful vaginal symptoms of menopause did not experience any greater improvement in their symptoms than women who received a "sham" therapy intended to appear like laser treatment, according to a new study.

The study, published in *JAMA*, investigated the potential effects of using fractional carbon dioxide laser therapy (*doi*: 10.1001/jama.2021.14892). This is a relatively new therapy that claims to treat vaginal and urinary symptoms of menopause.

About 40-60% of postmenopausal women experience these vaginal symptoms, which can include dryness, irritation, painful sex, and similar discomfort. Systemic hormone therapy (pills or shots) is a common treatment for these symptoms, but its safety is unknown in DES Daughters.

Local estrogen may be safer for DES Daughters—not enough research exists to be certain—but it might not work for everyone. Nonhormonal treatment options are limited, usually including vaginal lubricants or moisturizers.

Vaginal laser therapy has been promoted as a way to "rejuvenate" or "tighten" the vaginal wall after atrophy occurs following menopause. Practitioners insert a device into the vagina that shoots lasers at the vaginal wall.

The proposed way that it works is that it stimulates tissue growth factors and proteins in the vaginal tissue. That action is thought to stimulate new growth of collagen and the epithelial lining. However, this mechanism is theoretical. It has not been shown as the actual way that laser therapy works and is only a hypothesis.

In addition, studies on vaginal laser therapy have had mixed findings. Case studies and anecdotal reports have been positive from women who have had it (including a few members of DES Action). There have been very few randomized controlled trials, the gold standard for research into a therapy's effectiveness.

When laser treatment began growing in popularity a few years ago, the FDA issued a warning in 2018 stating that no laser therapy devices had been cleared or approved by the FDA to treat vaginal symptoms.

A meta-analysis of trials presented at the North American Menopause Society's conference this year did not find evidence of a benefit. However, most randomized controlled trials have not used a sham treatment.

Sham treatments are used instead of placebos when the treatment is a procedure instead of a medication. Women who receive the sham treatment do not know that they haven't received the real therapy.

The new study enrolled 85 postmenopausal women with vaginal symptoms that were severe enough for them to seek medical treatment for them. The laser group included 43 women, and the sham group included 42 women.

The participants received three treatments, performed 4-8 weeks apart. The device used was a fractional microablative carbon dioxide laser system.

The women were followed for one year and reported the severity of their symptoms on a scale of 0 (no symptoms) to 100 (most severe). They also filled out the Vulvovaginal Symptom Questionnaire (VSQ), with 20 questions about symptoms.

The researchers would consider the treatment successful if it reduced symptoms by at least 50% compared to those who received the sham treatment.

However, at one year after the procedure, there was no significant difference in symptoms between the two groups. Overall symptom severity in the laser group dropped by 17 points, and symptom severity in the sham group dropped by 27 points. The difference between these was not statistically significant.

Similarly, the differences in scores between the groups for the most severe symptoms and for the VSQ were not statistically significant. The laser group VSQ score dropped 3.1 points, and the sham group's score dropped 1.6 points. The average quality of life scores also did not statistically differ between the two groups.

The researchers also compared 46 tissue samples from vaginal wall biopsies in a subset of the women. Two women in the laser treatment group and three women in the sham treatment group showed a shift from postmenopausal-looking tissue to premenopausal-looking tissue.

Adverse events were similar in both groups. Vaginal pain occurred in 44% of women in the laser group and 68% of women in the sham group. Spotting occurred in 30% of the laser group and 5% of the sham group. Urinary tract infection occurred in 15% of the laser group and 5% of the sham group. In both groups, 11% of the women had vaginal discharge.

"Treatment with fractional carbon dioxide laser vs sham treatment did not result in improvement in symptom severity, quality of life, or vaginal histology," the authors concluded.

The research was funded by the Australasian Gynecological Endoscopy and Surgery (AGES) Society and the Royal Hospital for Women.

-TH

Makena

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account differences in their year of birth, sex, race/ethnicity, gestational age at birth, and birth weight.

The analysis also accounted for differences among the mothers' age, education, household income, number of previous children, and body mass index (weight).

In looking at specific types of cancer, children exposed in the first trimester to 17-OHPC were 5.5 times more likely to develop colon cancer than unexposed children. Risk of prostate cancer was similarly 5 times greater in exposed children.

The cancer with the greatest increased risk was pediatric brain cancer, which was 35 times more likely in exposed children than unexposed children. However, only two of the exposed children in the study had brain cancer, compared to seven of the unexposed children. Since pediatric brain cancer is already very rare, this increased risk would translate to very few additional cases.

Even when the researchers conducted additional analyses to look for other possible explanations for the increased risk of cancer, the results did not statistically change.

What makes these findings particularly frustrating—beyond their obvious echoes of DES—is that the FDA already withdrew its recommendation for 17-OHPC once before, in 1973, when the agency didn't find enough evidence to support its use in preventing miscarriage.

At that time the FDA even noted the possibility that the drug may increase risks of heart birth defects in children exposed to it during pregnancy. After removing all recommendations for its use during pregnancy, the FDA withdrew its approval entirely in September 2000, long after the drug had stopped being sold.

Yet over a decade later, the FDA licensed the drug again as Makena in 2011 under the accelerated approval program, despite shaky evidence on reducing preterm birth and a very small increase in stillbirths among mothers given the drug.

When a 2019 trial showed no reduced risk of preterm birth, many experts called for withdrawing the drug. DES Action has been particularly active in the effort to get 17-OHPC withdrawn, but no additional actions regarding the drug's approval or availability have changed, leaving women and their fetuses at risk without their knowledge or fully informed consent.

The study was funded by the National Cancer Institute and the National Institute of Child Health and Development. -TH

Your Legal Questions Answered

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to be separate and distinct, and you could not have known it existed, you can bring a new action," London said. So, if you previously received damages for an infertility suit years ago, and then you develop CCA or another condition that has been clearly linked to DES, you may be able to collect damages for the second injury as well.

Have any DES Sons or DES Grandchildren successfully brought a lawsuit?

Roman Silberfeld, an attorney who has handled more than 50 DES cases starting in the 1970s, said he took on a handful of cases from DES Sons with claims regarding testicular cancer, but the evidence for medical causation—proving that the DES exposure caused the cancer—was very weak, he said.

Ron Benjamin, an attorney in upstate New York who has handled many DES cases over the years, said he has settled a few cases on behalf of males related to testicular issues such as infertility, but they did not go to trial. One DES Action member tried to sue in a Third Generation lawsuit, but she lost the case "because there is legal precedent that liability can't go past one generation," she told us.

How long does the process take to start a case and follow through to the end?

Once a case has been filed, it usually takes about 12-18 months, give or take, London said. Attorneys who have been working on these cases for many years don't need to "reinvent the wheel," London said, because they know by now what needs to be done, which is all the more reason to find an attorney who already has experience with DES-exposure cases.

What are the typical amounts that are awarded in damages?

The settlements are confidential, so it's difficult to provide a range. "There's no amount of money that fixes the problem," London said, but his clients have been satisfied in the past. However, he's not legally allowed to reveal the amounts.

Can I sue the doctor or pharmacy or only the pharmaceutical company?

In most cases, the doctors who prescribed the DES are no longer alive, but even if they are, "it's really the drug company that's at fault," London said. DES was approved for women during pregnancy. Doctors were prescribing the drug as they believed it should be used and providing patients with the risks and warnings that the company provided to the FDA in the label's package insert.

"It's the drug companies that withheld information, including side effects, and contraindications, or did not provide adequate testing, so it's rare that doctors were misusing the drug, and it's not the pharmacist because they can't prescribe drugs," said London.

DES Action and Tight Lipped Partnership

DES Action and the nonprofit group Tight Lipped jointly hosted "It Hurts Down There!", a private virtual discussion of vulvovaginal (the entire vaginal area) and pelvic pain on November 16. Tight Lipped is a storytelling and advocacy organization fighting for people with chronic vulvovaginal and pelvic pain to be diagnosed correctly, treated effectively and given compassionate care.

Many DES Action members have shared their experiences of pain during vaginal exams, periods and sex. Though very common, this pain is often unspoken or accepted as "normal." Symptoms can include vulvar burning, rawness, itching and general pain. It can also include urinary tract infection-like symptoms, such as pain with urination, sitting and wearing tight pants.

Tight Lipped Executive Director Noa Fleischaker, DES Action Executive Director Suzanne Robotti, DES Action Community Manager Britt Vickstrom, and DES Action member Susan Desmarais led the group discussion and smaller breakout sessions. Participants shared their own experiences and expressed interest in future sessions. We're planning a second discussion on vulvovaginal pain that a medical professional will lead. Many thanks to Susan Desmarais for bringing our two groups together!

Significant Silicone Leakage From Breast Implants

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to reproductive toxicity and endocrine disruption.

The study followed 389 women, with an average age of 50, who had silicone breast implants. The women all underwent removal or revision of their implants between 1986-2020 at the same clinic in the Netherlands.

During the procedure, the researchers collected tissue samples from the women's lymph nodes and from the capsule around the implants.

After a woman receives breast implants, scar tissue will form around each one to create a tissue capsule. This protective capsule keeps the implant in place. However, if the implant leaks silicone gel, it may end up in the capsule.

Most of the women provided both tissue samples, but 24 women had only lymph node tissue removed.

The scientists were looking for whether silicone particles existed inside or outside the capsule. Nearly all of the women—98.8% of the participants—had silicone particles present in the tissues, which indicated silicone gel leaking from the implants.

In 86.6% of the women, the researchers found silicone particles in the tissues surrounding the capsule and/or in or around the lymph nodes. This finding suggested not only that the implants leaked some of the silicone gel, but that it had migrated through their tissue. Only 12% of the women had silicone particles exclusively within the capsule, indicating no leakage to the surrounding tissue.

Most of the women (92.%) also had evidence of an inflammatory reaction in the tissue, indicating that the immune system had recognized the silicone particles as foreign and attempted to destroy them.

The researchers also investigated whether there were any differences in the findings between women with different types of implants. One group included 46 women who had cohesive silicone gel breast implants, and the other included 343 women with either an older or newer type of implant.

However, the researchers did not find any significant differences between the groups in the amount of silicone gel bleed or migration of the silicone particles. The researchers also did not find any differences in silicone spread based on the women's ages.

In six of the women (1.5%), the researchers found BIA-ALCL cancer.

The researchers acknowledge that scientific debate still exists regarding whether silicone breast implants can cause breast implant illness. They also point out, however, that many women who had their silicone breast implants removed then experienced an improvement in their symptoms, suggesting a causal relationship.

In a commentary that accompanied the study, a pair of Dutch physicians pointed out some of the study's limitations. For example, the study authors did not report if the implants were ruptured or intact.

The editorial also notes that the women in the study are not likely to be representative of women with implants in the general population. These women went to the clinic specifically to have the implants removed or adjusted, so that suggests they were already experiencing some symptoms or other problems.

That means it's not possible to say whether silicone leakage occurs in all women with implants or only in those who experience symptoms that lead them to request implant removal or replacement.

The authors also noted that it's still not clear what it means that silicone particles were found in the tissue. They highlight the importance of continuing this research.

"As we wait for these studies to be carried out, there is probably room for more transparent information to women who are considering or already have breast implants," the editorial authors wrote. "This transparency is vital to improve informed decision-making regarding the likelihood of silicone deposition in tissues adjacent to and distant from the implants." - TH

DES Action® VOICE

DES Action USA
229 E. 85th St., Unit K
New York, New York 10028

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New Study Finds Significant Silicone Leakage From Breast Implants

DES Daughters have a 30% increased risk of breast cancer from ages 40 to 50, then their risk is equal to non-exposed women. Researchers have not yet determined whether DES Granddaughters similarly have any increased breast cancer risk.

Therefore, in addition to following DES-related research, DES Action reports on research related to breast implants as well. The risks of breast implants have not been adequately studied over the years, and this issue affects DES Daughters who have needed mastectomies due to breast cancer.

There is growing controversy over breast implants due to an increasing number of women complaining about a variety of symptoms that appear to be caused by the implants. Some doctors are now taking these complaints seriously and are calling it "breast implant illness." The spectrum of symptoms include: brain fog, hair loss, fatigue, chest pain, sleep disturbances, irritable bowel syndrome, headaches, chronic pain, and autoimmune diseases such as lupus and fibromyalgia.

A new study published in *JAMA Open* now provides additional evidence of potential harms from silicone breast implants (*doi*:10.1001/jamanetworkopen.2021.25381). Despite being on the market for about 60 years, the possible harms of silicone breast implants have only recently received more attention from researchers.

Past research had already determined that a very rare cancer has been associated with silicone breast implants. Breast-implant-associated anaplastic large cell lymphoma (BIA-ALCL) is a rare complication, but rates have increased, the study authors noted.

So far, research has been limited, but at least one previous study did find a higher risk of autoimmune disease in women with implants. The authors of this study noted that silicones can trigger an immune response.

They explain that silicone gel can biodegrade or bond with water molecules that breaks the gel down into cyclic silicones. These are a different group of silicones, some of which have been banned in Canada and Europe because they've been linked

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