



Cervical Cancer Risk Increased for Some.....	3
Solutions Exist for Vaginal Dryness and Painful Sex.....	4
DES Action USA 2015-2016 Fiscal Year Annual Report.....	6

## A Focus On Diethylstilbestrol

WINTER 2017 #151

# Two DES Symposia Coming This Spring

**A**fter months of planning from DES Action USA, two symposia will be held this spring to discuss DES issues of the past, present and future.

On March 2 at 5:30 pm, Mount Holyoke will be the site of a student-faculty symposium that will explore and educate a new generation about how DES was a mass experiment on millions of pregnant women without their consent or knowledge of risk. Why would the FDA approve DES? What have we learned about environmental exposures and endocrine disruptors starting with DES? These are some of the questions we will address.

The symposium is presented in collaboration with the Five Colleges Reproductive Health, Rights and Justice Program and the Five Colleges Women's Studies Research Center. The Five Colleges Program melds the students and professors of Smith College, Amherst, Hampshire College, UMass at Amherst and Mount Holyoke. The program is in South Hadley, Massachusetts, and is open to the public. It will be held in the Cleveland Building in room L2, and parking will be available. We especially hope our DES Action members can attend. Details are on our website.

The night before, March 1, DES Action has been asked to present the same issues to the Boston-based Group for Reproductive and Health Rights at Boston University. It may not be open to the public, but we hope to be allowed to invite a small

group. If you live in the Boston area and would like to attend, please email Karen@DESAction.org and she will do her best to get you an invitation. The exact location and hotel discount information are on our DES Action website.

"We are thrilled to be invited onto these two campuses to teach and inspire students who might well discover they are third generation DES-exposed and have never known," notes Suzanne Robotti, executive director of DES Action USA. "Part of our mission

is to keep another DES incident from happening, and educating these energetic students and faculty about how it did happen and what their role can be in preventing it is very exciting."

A DES Action volunteer, Karen Calechman, became determined to create this symposium when she realized the DES Action historical archives are now housed at Smith College. A graduate of Mount Holyoke herself, she discovered her exposure to DES while an

*continued on page 7*

## NIEHS 50th Anniversary Partners Meeting

Issues related to DES exposure were once again included in discussions at the annual meeting of NIEHS (National Institute of Environmental Health Sciences) Partners on Nov. 17. The Partners include nonprofit representatives and health advocates who meet in person once a year with officials from the NIEHS and National Toxicology Program (NTP) Director Linda Birnbaum, Ph.D. The NIEHS was formed to study and prevent diseases from environmental exposures, such as DES.

In honor of NIEHS's 50th anniversary this year, the Partners met at the NIEHS

campus in Research Triangle Park, North Carolina, instead of the usual Washington, D.C., location. This setting allowed the Partners to tour the NIEHS laboratories and other facilities and to meet eight NIEHS researchers in person.

"For me, as well as many of the NIEHS Partners, this was our first time visiting the campus, even though most of us have been the representatives from our organizations for over 10 years," said Kari Christianson, the DES Daughter and long-time DES Action activist who represents DES Action USA at the meeting. "So this was a special opportunity to meet with many more of the

*continued on page 8*

# JOIN THE CONVERSATION

## New Member Benefits!

Part of our upgrade to the DES Action USA website includes a new members-only area. As a member, you'll be able to log in to the Members Area for access to:

- **Searchable Doctor Listings** — If you are looking for a DES-aware doctor in your area, you can go to the members-only searchable Doctors List and search by city, state or ZIP code. You'll find doctors' names, practice names, specialties and contact information. These listings have been created by recommendations from DES Action members.
- **VOICE Newsletter** — current and historical. The VOICE is the most popular member benefit of DES Action. Now access all 36 years of newsletters and search for any topics or articles you need. The VOICE documents the history, the science and the personal stories

of DES and all of us who were exposed.

- **Attorney List** — If you're interested in getting involved in possible future DES-related litigation, we offer a list of knowledgeable attorneys DES Action members have shared with us who might be able to help.
- **Exclusive Content** — an expanding collection of articles and videos accessible only to current DES members.

**And more!** Update your mailing address, pay your membership dues or make a donation online.

## DES Action USA on Facebook

Like DES Action USA on Facebook and follow us on Twitter to stay up to date on medical and environmental health news that affects you, your loved ones and the planet. Share your thoughts with an engaged and active community. There's a ton of information swirling online 24/7 that affects the

DES population — don't let it pass you by!

## Online Support Group for DES Daughters

Here is a safe place for discussing very personal issues that arise for DES Daughters. We live in the farthest reaches of the country but have developed a sense of community together, via our email listserv.

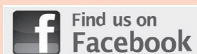
What we talk about is private — just between us — so we can feel free to raise questions on topics we aren't comfortable bringing up with others. What is amazing is the depth of knowledge in the responses.

It's a terrific resource for information and support from DES Daughters who wrestle with the effects of menopause, family relationships and medical diagnosis issues specific to DES exposure. To join the support group, send an email to: [DESactionDaughters-subscribe@yahoogroups.com](mailto:DESactionDaughters-subscribe@yahoogroups.com).

## New Website Information

We're changing to a new membership program to improve our service. The big thing to know is that we've reset the passwords. The new default password is: **desUSA?&B5V**

You'll find the same great content: a searchable list of doctors, a list of lawyers, and back issues of the VOICE in flipbook and pdf formats.



## MISSION STATEMENT

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

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Published quarterly by:

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#### MedShadow Foundation, Inc.

**President** ..... Suzanne B. Robotti  
**Digital Director** ..... Deirdre Wyeth  
ISSN 1522-0389  
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# Cervical Cancer Increased Risk for Some

## *No extra risk for those with no physical defects*

A long history of research has clearly established the link between DES exposure and an increased risk of clear cell adenocarcinoma of the vagina and cervix. But other cancers can affect female reproductive organs, too. Scientists haven't spent as much time exploring how much the risk of these cancers might relate to DES exposure. A new study in the journal *Gynecologic Oncology* investigated the risks of invasive cervical cancer other than clear cell adenocarcinoma. The study also looked specifically at whether risk differs for women who have physical abnormalities as a result of their DES exposure.

### **How They Did the Study**

Aside from clear cell adenocarcinoma, DES Daughters' risk of cervical cancer is about average for those with no organ anomalies, the study found. Among those with physical, structural abnormalities from DES exposure, however, risk for any dysplasia and for invasive cancer was increased, though it's not clear how much.

The researchers used data from a national medical database in the Netherlands to track 11,895 women from 2000 to 2008. All of the women had reported a history of DES exposure. It was difficult or impossible to verify the DES exposure of most of the women, especially since older hospitals' and doctors' records had long since been destroyed or lost. Only 115 of the women in the study had sufficient documentation to verify their DES status. The researchers included all women in their analysis, even if they lacked documentation of DES exposure, since past research had shown that most people accurately self-report DES exposure.

The researchers also collected

information on the women's educational level, the reasons their mothers took DES during pregnancy (if known), their age at their first gynecological exam, and how many screening smears or colposcopies they had undergone in the five years before the study. Only women age 29 and older were included because the Dutch screening program is only available to women between ages 30 and 60.

### **Types of Physical Abnormalities Included**

The women filled out a questionnaire about their health and medical history that included detailed questions about any possible reproductive tract abnormalities. These included the following:

- adenosis — having glandular or endometrial tissue — of the vagina or the outer, lower part of the cervix that bulges into the vagina, called the ectocervix.
- squamous cell metaplasia, which refers to changes in the shapes of cells lining the surface of the cervix or vagina, from a normal shape to a squamous, or scaly, pattern.
- transverse vaginal ridges, which refers to ridges in the mucous membrane of the vagina that allow the vagina to stretch during childbirth, for example.
- cervical shape abnormalities, which exist in one third of women with DES exposure and include cockscomb, cervical hoods and cervical collars. A cockscomb cervix refers to the cervix having an outer ridge in the shape of the crest atop a rooster's head. A cervical collar means the cervix has an outer collar of sorts around the circumference of the cervix, and a hood is like a partial collar, a

fleshy extension that looks like a hood.

- pseudo-polyps, which look potentially cancerous but are not.
- hypoplastic cervix, a smaller than typical cervix.
- uterine cavum malformations, which refer to abnormal shape or fleshy parts on the uterus.
- tubal malformations of the fallopian tubes.

### **What They Found**

Three percent of the women in the study overall had cervical cancer or a cervical lesion that could be precancerous. The researchers characterized the different levels of dysplasia, or abnormal cell growth, as CIN (mild dysplasia, or potentially precancerous cervical lesions), CIN2 (moderate dysplasia), CIN3 (severe dysplasia or carcinoma, which is cancer in the tissue lining), and cervical cancer, either of the

**"Overall, DES Daughters were 2.8 times more likely to have mild dysplasia than the general population."**

invasive cervical squamous cell carcinoma type or non-clear-cell adenocarcinoma. CIN2+ referred to having CIN2 and CIN3 or cancer.

Overall, DES Daughters were 2.8 times more likely to have CIN — mild dysplasia — than the general population. Their risk of CIN2 or CIN3, however, was not statistically greater than that of the general population. The risks were greater for all these outcomes, however, with women who had malformations as a result of their

*continued on page 7*

# Solutions Exist for Vaginal Dryness and Painful Sex

One of the least discussed changes that can result from menopause is also one that can have some of the biggest negative impacts on women's personal lives: vaginal dryness and irritation and, often with it, pain or bleeding during sexual intercourse. The medical

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**"No woman should have painful sex."**

**—Dr. Lauren Streicher**

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term women may have heard for this condition is vulvovaginal atrophy, which refers to the changes that can occur in the vulva and the vagina after menopause. These changes occur because of a drop in estrogen levels. Vaginal dryness can lead to reduced desire to have sex or difficulty with penetration. A complaint we've heard from DES daughters is the dryness makes internal exams extremely painful.

In 2014, however, menopause societies expanded and renamed this condition to "genitourinary syndrome of menopause" (GSM), which women may hear instead. GSM refers to any symptoms related to the drop in estrogen levels and other sex steroids in the female reproductive system, including pain or burning during urination and recurring urinary tract infections.

## **No Women Should Have Painful Sex**

"The number one message is that too many women are told there is no treatment, that this is just something they have to put up with it," said Dr. Lauren Streicher, M.D., an assistant clinical professor

and medical director of the Center for Sexual Health and the Center for Menopause at Northwestern University's Feinberg School of Medicine. Because she received her training in Chicago, Streicher is very familiar with the effects of DES exposure. The University of Chicago is where Dr. Arthur Herbst worked after he published the groundbreaking medical study in 1971 about the cancer risks of prenatal DES exposure. Streicher therefore learned more about DES exposure in medical school and training than most other doctors do, and she treats a higher proportion of DES Daughter patients than is typical.

"Many women decline treatment, but the majority of women aren't offered treatment or don't even know there is treatment," said Streicher said about vulvovaginal symptoms and pain during sex. She also authored the book "Sex RX." "This is very easy to treat, and no woman should have painful sex."

Another reason women don't talk to their doctors or their partners about their difficulties is embarrassment. One in five women in a different study were too embarrassed to talk to their partners about dryness and pain in the vagina, and just over half didn't talk about it because they thought it was just a natural part of getting older that they couldn't do anything about. The result, in that study, was large percentages of women (often close to or more than half) having sex less often, having less satisfying sex, putting off sex, having painful sex, and having reduced sexual desire.

## **A Good Lubricant Is The First Place to Start**

"Lubricants don't change

tissue, but if a person has mild changes in the vagina, then a good lubricant can make all the difference," Dr. Streicher said. Water-based lubricants rarely cause irritation but dry out relatively quickly. Petroleum-based lubricants may cause vaginal irritation and should not be used with condoms, diaphragms or cervical caps. (Keep in mind that any lubricants with added bactericides, spermicides, warming substances or other enhancers may cause irritation.)

In the category of natural oils, many DES Daughters have told us that coconut oil works well for them and use it every day for general comfort and to make internal exams less painful, not only for sex. Because it can be messy, some have suggested using a "cot" or rubber tip on the finger to insert the oil. Others suggested freezing coconut oil in mini-ice trays and inserting them into the vagina so the oil is absorbed slowly. The coldness of the frozen oil doesn't seem to cause discomfort. Other natural oils generally recommended include avocado, olive, corn and peanut oils, but like petroleum lubricants, can cause staining. (If you're a member of our DES Daughters Chat Group, you can search and find a detailed discussion of using coconut oil vaginally).

Silicone-based lubricants are what Dr. Streicher recommends. The advantage to silicone-based lubricants is that they are more slippery and last longer. One option she recommended is Replens, a long-acting moisturizer that is applied inside the vagina twice a week to increase lubrication and elasticity. Another used at the time of intercourse is Wet

Platinum, which many drugstores carry. (Most other silicone-based lubricants are only available online or at boutique shops specializing in sex-related products.)

She emphasized that lubricants should be used for both the vagina—the inside—and for the vulva, the outer area. “Women will use a lubricant inside the vagina, and meanwhile they can’t even initiate intercourse because the opening to the vagina and vulvar tissues are so dry,” Dr. Streicher said. “They’re two different areas that need to be treated differently.”

### **Hormones Are One Option, Even for DES-Exposed Women**

Although systemic menopausal hormone therapy does effectively treat these problems, many women with a DES history are understandably uncomfortable taking hormones (an estrogen or estrogen+progesterone pill that increases hormone levels in the body), especially since studies on the effects of hormone therapy on DES Daughters are lacking.

Evidence is also lacking on DES Daughters’ use of the most commonly prescribed treatment for vulvovaginal atrophy: a smaller, local dose of vaginal estrogen. However, some DES Daughters might still choose to try local estrogen, depending on their symptoms and risk tolerance, given what is known about it. Local vaginal estrogen options include vaginal creams (Estrace or Premarin) and the vaginal ring (Estring), both containing 17-beta estradiol. The vaginal tablet (Vagifem) contains estradiol hemihydrate.

A review of 30 randomized controlled studies by one of the highest-quality organizations, the Cochrane Group, found that vaginal estrogen reduces the symptoms of vulvovaginal atrophy. A handful of studies have looked at the use of vaginal estrogen along with a testosterone cream.

These studies found improvement in sexual function, reduction in pain, and especially an increase in arousal, desire, and satisfaction when testosterone was included with estrogen.

One concern DES Daughters or other women might have is how long the estrogen from local use stays in the body. In one study, the vaginal ring and the vaginal tablet reached their peak absorption at 8 hours after administration, with estrogen levels dropping back to where they started by 12 hours. Using these products on a regular basis can increase overall estrogen levels in women, though the amount is lower than with systemic hormone therapy. The levels do not exceed 20 pg/ml, the normal range of estrogen after menopause.

The most obvious question for using vaginal estrogen is safety. No studies have assessed whether vaginal estrogen is safe in women with a DES history. The American College of Obstetricians and Gynecologists has published an opinion, however, on vaginal estrogen use among women with a history of breast cancer, and those guidelines may be helpful for DES Daughters in making their decision over whether to try vaginal estrogen. ACOG concluded, “Data do not show an increased risk of cancer recurrence among women currently undergoing treatment for breast cancer or those with a personal history of breast cancer who use vaginal estrogen to relieve urogenital symptoms.” Nevertheless, the ACOG committee recommended that non-hormonal approaches be first-line choices in women during or after breast cancer treatment, just to be cautious. If non-hormonal options aren’t sufficient, ACOG recommends using the lowest doses of vaginal estrogen possible that are effective. Individual doctors and their patients may make a case-by-case decision, particularly since no research has shown safety problems so far.

A brand-new drug just approved by the FDA for vaginal dryness does not have estrogen, but it does have a different hormone. DHEA prasterone is a sort of precursor to estrogen and comes in a vaginal suppository.

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**“Lubricants don’t change tissue, but if a person has mild changes in the vagina, then a good lubricant can make all the difference.”**

**—Dr. Lauren Streicher**

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### **Non-Lubricant Alternatives to Local Hormones**

If lubricants do not treat the problem well enough, especially if the dryness is more severe, one non-hormonal prescription medication option is Ospheña. This oral medication stimulates estrogen receptors and works as well as a local vaginal estrogen to alleviate dryness and pain, but it is not a hormone. The possible risks of Ospheña are based on risks seen in other drugs of its class; the most serious were blood clots and hot flashes. Many have heard of vaginal rejuvenation, which is a non-medication option using a CO2 laser, the Mona Lisa Touch. These lasers have FDA clearance, which means they have been okayed for safety, but they do not have FDA approval to treat any specific condition. CO2 lasers for vulvovaginal atrophy have been used in the U.S. for about 3–4 years, with about 25,000 treatments delivered so far.

The MonaLisa Touch is a wand that gets rotated in 60 directions in the vagina, and then a separate probe is used to treat the vulva and the opening of the vagina.

*continued on page 7*

# DES Action USA 2015-2016 Fiscal Year Annual Report

As DES Action USA looks forward to the new year ahead, it's worth briefly reflecting on all that was accomplished in 2016. The history and health issues related to DES exposure benefited from important media attention this past year, including a large online feature in *Broadly*, several op-eds by DES Action USA Executive Director Su Robotti, and media outlets reporting on the potential link between DES exposure and being transgender. In addition, a nice way to conclude 2016 has been the news of Robotti's appointment to the Food and Drug Administration's Advisory Committee on Drug Safety and Risk Management. Robotti's term starts February 15 and will last until May 2020.

Other exciting developments from 2016 included the establishment of the DES Archives at Smith College's Sophia Smith Archives of Women's History and the planning for the upcoming symposia, "DES: A Population Health Tragedy." The archives, overseen by curator and DES Granddaughter

Jen Bolmarcich, will ensure that the history of DES does not fade into the background of medical and human history. Instead, anyone will be able to visit and peruse the archives to better understand the damage the drug wreaked and the experiences of those living with DES exposure.

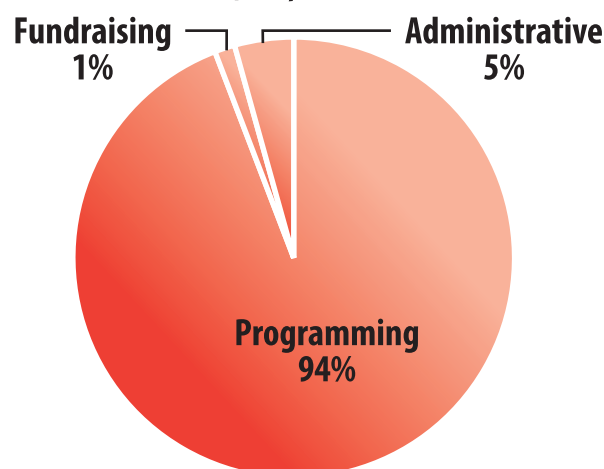
Meanwhile, research continues in an attempt to understand what effects DES might have as those exposed grow older. Some of that research into understanding DES's mechanisms may become easier in the future with the development of "Evatar," the organ-on-a-chip program developed at NIEHS to better model how various chemical exposures affect the female reproductive system.

For the fourth year in a row, DES Action USA has been named a Top Rated Nonprofit by Great Nonprofits on Guidestar's website. This honor is based on public comments and therefore means a lot to us. We continue to strive to make improvements in our members' experience and access to information and resources.

**2016 Fiscal Year Revenue**  
**\$68,718**



**2016 Fiscal Year Expenses**  
**\$76,576**



## **DES Symposia**

*continued from page 1*

undergraduate.

The researchers, doctors and advocacy pioneers that these students will become, Calechman said, will be integral to continuing research. Too many unanswered questions remain about the effects of DES exposure, not only in DES Daughters but in the third generation, she said.

“As always, in science, more studies and experiments lead to new questions, which then lead us to

some answers,” Calechman said. “As epigenetics continues to progress in relation to DES exposure, I hope it shines more light on the conditions and outcomes for the DES-exposed.”

Some of the speakers will include DES researcher Julie Palmer, Sc.D., Associate Director, Slone Epidemiology Center, Professor of Epidemiology, Boston University School of Public Health, Kari Christianson, past DES Action President, and Jen Bolmarcich DES granddaughter and archivist for

DES Action at Smith College.

“DES is not a history lesson,” Christianson said, “It is an environmental health issue that continues to affect not only the millions in the DES-exposed community, but also everyone who eats, drinks and breathes on this planet.”

All are welcome, see further information on our website and please send us an eMail to let us know to expect you. Email: Su@DESAction.org

**DES VOICE**

## **Cervical Cancer Study**

*continued from page 3*

DES exposure. About a third (32%) of those with DES-related malformations had precancerous lesions or cervical cancer, compared to one in five (20%) of those without malformations.

Among women with adenosis or squamous cell metaplasia of the vagina or ectocervix, the risk of precancerous lesions was more than four times greater than in the general population. They were also 1.7 times more likely to develop CIN2, CIN3, or invasive cancer. This type of abnormality was most associated with abnormal cell growth.

### **Possible Reasons for the Findings**

In some studies, if those who are more likely to get screened are those who are already more at risk, finding a greater likelihood of developing the cancer may

reflect the fact that more of them are choosing to get screened than people who have a lower risk.

It is also possible that some of these women had a higher rate of diagnosis because a higher proportion of them were undergoing screening in the first place. As we’ve found with breast cancer, more screening leads to more diagnoses.

“A high frequency of screening might lead to overdiagnosis of CIN lesions that have a high chance of regression,” the authors wrote. “More intensive screening in DES daughters with vaginal/cervical epithelial changes (through smears and colposcopic surveillance) may cause overdiagnosis of CIN2+” because lesions might be identified that would go away on their own, or the way the abnormalities look might be misinterpreted as lesions or cancer.

“Whether the observed increased

risk of CIN2+ is real or an artifact [result] of screening could not be detangled,” the researchers wrote. “Most probably, both are true and a real small increased risk of CIN2+ is somewhat enlarged by intensive screening.”

In other words, the overall risk was probably still higher for those with these cervical and vaginal abnormalities, even if it’s difficult to parse out how increased the risk is. The positive findings from the study are that DES Daughters in general do not have an increased risk of cervical cancer than the general population outside of clear cell adenocarcinoma.

“Our findings underscore the importance of being cautious with respect to invasive diagnostic procedures or treatment since overdiagnosis seem to occur in a group of women which is already strongly medicalized,” the researchers wrote.

**DES VOICE**

## **Vaginal Dryness and Painful Sex**

*continued from page 5*

The treatments are delivered three times, six weeks apart, and they basically restore the vagina to pre-menopausal condition, Dr. Streicher said.

“We see three changes: a change in tissue, a decrease in pain, and alterations in pH,” she said. “The pH goes up in women with postmenopausal dryness, but when

you do biopsies in women after CO2 laser treatments, it looks like it did before menopause.”

The lasers also come with downsides, starting with the cost: it’s about \$2,000–3,000 to do a complete set of cycles. This cycle is effective for at least 12 months, but none of the studies currently have data past 12 months so far. The manufacturer recommends a “booster” treatment once a year, but

it’s not clear yet from the evidence whether that’s necessary.

Dr. Streicher emphasizes that enough options exist, both with and without hormones, that any woman should be able to find relief from her symptoms.

“The number one message is that too many women are told there is no treatment, that this is just something they have to put up with it,” she said.

**DES VOICE**



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## **NIEHS 50th Anniversary** *continued from page 1*

researchers that we have ‘met’ on our monthly conference calls.”

“Research at the NIEHS leads to a broader understanding of the adverse health and reproductive effects of DES and other similar endocrine-disrupting chemicals,” Christianson said. “It was great to see how intentional everyone at NIEHS is about encouraging the next generation of environmental health researchers and scientists.”

DES exposure was mentioned in several presentations since “knowing about and preventing a similar health disaster remains in the forefront of everything that the NIEHS does,” Christianson said. “DES is not a forgotten history among these researchers.”

With all of the ongoing research related to the adverse health experiences of DES Daughters, Sons and possibly Grandchildren, Christianson said the Partners

play an important role in bringing their experiences, questions and concerns to the researchers.

“It’s our hope that this interaction between the researchers and the communities that we represent continues to be strong,” she said.

**DES VOICE**

