

Continuing The Action

DES Action Looks To The Future

To our Dear DES Action Friends and Supporters —from Martha Cody:

I write to announce an exciting new chapter in the life of DES Action USA. But first, some background.

As many of you know, my late mother Pat Cody helped to found DES Action over 35 years ago, after learning of the effects of DES on me, her first-born child. I joined the Board to carry on her legacy of activism. Soon after I came onto the Board, we (together with the DES Action staff) created a strategic plan for our organization, which identified the ways we might ensure a solid future.

We identified many strengths of DES Action USA and what makes it special:

- Founded and run by and for the DES-exposed
- Seeing ourselves (the DES-exposed) as activists and agents of change, not just victims
- Claiming a seat at the table for consumers during important medical, legislative, and community health discussions
- Keeping our members first and foremost in our minds, and never allowing financial pressures or inducements to shake our commitment to serving our members and telling the truth
- Combining grassroots passion with a scrupulous attention to the medical facts and research findings, so that all of our work with medical researchers, legislators, and our members carries the utmost credibility
- Making the connections between the DES story and other



Martha Cody and Su Robotti

current issues, from the over-prescription of hormone replacement therapy to endocrine disruptors in our environment

- Working in coalition with allies, both within the U.S. and internationally, to defend consumer rights and prevent a DES-like tragedy from ever occurring again

However, we also recognized the realities we faced of being a small (although mighty) group with only two staff members and a finite number of likely members and supporters. So with that understanding we identified ways to continue serving our supporters, both in the short and long term.

Then this year, after 10 years of amazing service in staff capacities, both Executive Director Fran Howell and Program Director Kari Christianson announced their decision to retire. This forced us to bring forward plans we thought we wouldn't have to execute for at least another 5–7 years—to find another organization to assume responsibility for DES Action USA, an organization that would commit to carrying on our legacy and continuing

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Dear Fellow DES Action Supporters —from Su Robotti:

Speaking for the staff of MedShadow Foundation, we are thrilled to join forces with DES Action. Our mission is to gather information on the side effects and long-term effects of medicines and then make it easy to find on the MedShadow.org website. Our mission dovetails with the mission of DES Action—to educate and empower the DES-exposed. We intend to carry on the work of DES Action and continue the website as it is, the VOICE newsletter and the support you've received from DES Action for more than 35 years.

I founded MedShadow just under two years ago because I'm a DES Daughter. DES left my body infertile. For many years I was angry at the drug company, at the FDA and especially at my mother's doctor. Life goes on and DES' impact drifted to the back of my mind. Ten years ago my husband and I took guardianship of my nephew; he was 12 years old. Soon after enrolling in his new school in our town, the principal called and demanded that we put him on Ritalin. He was "off the scale ADHD," the principal said. I took my nephew to an ADHD doctor who quickly wrote out a prescription for Ritalin. I asked if it was safe. "Absolutely," the doctor swore. I

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JOIN THE CONVERSATION

Facebook For All

With lots going on in the DES community, you can be part of the information flow 24/7. Social media has changed the face of communicating, and DES Action USA is part of it.

Stay on top of information of interest to the DES community and share your thoughts.

Timely — Accurate — Interesting

Check out the DES Action USA Facebook page where we're sharing lots of ideas and information.

- The choice to give birth was taken from some DES Daughters while others chose not to. Scrutiny is given to whether women raise children and actress Jennifer Aniston stood up to it.
- Australian researchers begin unraveling the cause of preeclampsia (high blood pressure during pregnancy). DES Daughters are 1.4 times more likely than unexposed women to develop it. Still to be learned, why DES Daughters are at increased risk.
- Robin Williams—why? He was amazing and our hearts broke with his death. Sadly, depression's demons are real and those exposed to DES are at increased risk. Please take it seriously.
- You've heard it before—go take a walk. New research shows walk-

ing just 30 minutes a day lowers post-menopausal breast cancer risk. With their higher risk for the disease DES Daughters want to do what they can to prevent it. Walking—good medicine with no adverse side effects!

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.



Find us on
Facebook

twitter

We are a caring and supportive group that has become an important benefit of membership in DES Action USA. To join the support group, send an email to:

DESactionDaughters-subscribe@yahoogroups.com

Once we've checked to be sure you are a DES Action USA member, please join us and participate in the email conversations surrounding the impacts of DES exposure and know your concerns are completely valid. It's empowering knowing you are not alone!

MISSION STATEMENT

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

DES **VOICE**
Action

Published quarterly by:

DES Action USA

P.O. Box 7296
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ISSN 1522-0389

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Printing

CPMM Services Group, Columbus
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Martha Cody

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to serve our members.

After a thorough evaluation process, the Board voted to transfer responsibility for DES Action USA to MedShadow Foundation (medshadow.org), whose founder, Suzanne Robotti, is a DES Daughter and a former board member of DES Action. Here's a summary of why we chose MedShadow Foundation as our successor organization:

- Its focus on the side effects of pharmaceutical products and devices is a natural fit with DES — the original example of a medication with hidden, harmful side effects
- Its passion, borne of personal experience, for this cause
- Its commitment to serve our members, maintain their privacy, and refuse drug company funding
- Su's first hand knowledge of DES, its medical impact on those exposed, and the community that DES Action USA has become

From your perspective, the DES Action you've so generously supported all these years will not be significantly

different in the future. Importantly, the DES Action website, the VOICE and the DES Daughter's Online Support Group listserv, three resources our members have told us they greatly value, will still be there for you. AND you will also have access to a wealth of content MedShadow amasses on drug side effects and interactions.

While we could never replace the personal relationships many of you fostered with Fran and Kari, MedShadow's staff will be there to respond to your questions and calls. And Kari will provide MedShadow with a critical link to researchers as she intends to continue her involvement on research committees, including the NCI DES Follow-up Study.

Thank you for your loyalty and support over the past 35 years. We hope that you will join us in supporting MedShadow as it takes on the DES Action USA mission and carries it into the future.

Warmly,



Martha Cody
President, DES Action USA

Su Robotti

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asked about the long-term effects. "None," he said. I asked for the studies to prove that. He said there were no studies, "We've been giving this drug to kids for 20 years. If there was anything wrong with it we would know."

Really? I needed more assurance than that. My husband and I weren't even convinced that our nephew had ADHD; he seemed like a 12-year old with some issues. Our nephew never got the Ritalin. He had a tough time in school and had to learn how to work things out. There are kids who need ADHD medicines, but we felt for our nephew it was a bad diagnosis. It took a lot of work, but he's in college now and is a great kid.

That's why I started MedShadow Foundation. We

want everyone who takes a medicine or a supplement to discuss the benefits and risks with their doctor in order to make the decision for their families.

Together DES Action and the MedShadow Foundation will continue to grow our presence online and in social media. We will continue giving you the information you need on DES research and the ongoing effects that DES has in our lives and future generations. Please contact me directly with your thoughts, comments and hopes for DES Action.

Best,



Su Robotti
President, MedShadow Foundation
Su@medShadow.org

Osteoporosis Protection Different For DES Daughters

"Menarche, Menopause, Years of Menstruation, and the Incidence of Osteoporosis: The Influence of Prenatal Exposure to Diethylstilbestrol," Samantha E. Parker et al. *Journal of Clinical Endocrinology & Metabolism* 2013, 10.1210/jc.2013-2954

Reviewed by Fran Howell

During years women menstruate, the estrogen pumped through their bodies has a preventive effect against bone disease, the most common type being osteoporosis. Fractures and weakened bone mineral density are often seen in menopause, after estrogen production dramatically decreases. The more years a woman menstruates, the greater her protection against osteoporosis.

This study, conducted by researchers with the National Cancer Institute DES Follow-up Study, examined bone disease occurrence between DES-exposed and unexposed women. They compared the number of years from menarche (age of first menstrual period) to menopause to determine if DES exposure alters the expected decreased risk for osteoporosis that a woman's lifetime estrogen production provides.

All women who experienced fewer than 25 years of menstruation had a higher incidence of osteoporosis than women who menstruated for 35 years or longer. But the natural protection of estrogen during reproductive years was weaker for DES Daughters than for unexposed women.

Beginning menstruation early (11 years old or less) was

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*This article, by DES Mother **Joan Stear**, is another in a series of personal stories to be published in the VOICE. Stear lives in Australia and her compelling thoughts echo those of so many DES Mothers everywhere. We reprint this with permission from DES Action NSW, which ran these thoughtful reflections in The DESfactor newsletter.*



Joan Stern

I am a DES Mother—89 years old and thankful I am able to give this testimony. I wish to describe my experience with the drug DES, known as “diethylstilboestrol.” I want all who read this to know my

serious concerns for the many thousands of Australians, and others around the world who have been affected by the DES disaster and who have been deserted in the main by health authorities.

I was prescribed DES during pregnancy with my daughter because I had two previous miscarriages. Following these miscarriages, I had already been prescribed DES for a pregnancy, which resulted in my having a stillborn baby at eight months. The DES dosage for the pregnancy with my daughter was gradually increased to the point of my taking about 27 DES tablets every day. My impression was that DES prescriptions were commonplace, with some of my friends and relatives also given DES

during pregnancy.

I first learned about the harm caused by DES in the early 1970s by way of a casual flip through a magazine. The thought that a drug I had taken might jeopardize my daughter’s health and her prospect of having children gave me pangs of guilt beyond words. I expect this scenario would be beyond the worst imaginings for many mothers. Finding the words to tell my daughter was agonizing, but there was peace of mind that by her knowing, she would be equipped for whatever fate DES might dish out to her.

My daughter went on to have child-bearing problems and losses due to DES. The hardest part for her was in getting medical professionals to pay attention to her concerns. They either had never heard of DES or were dismissive.

For her the physical trauma of this drug paled into insignificance compared with the trauma of her DES exposure going unrecognised, and without validation, by the medical fraternity and the community at large.

The way I learned about DES is a case in point—the reliance on finding

the right magazine, at the right page, at the right time. And this slipshod method continues today, but now without the timeliness in receiving DES information, thus adding to the disaster.

The most troubling thought to me is that the DES-exposed have suffered or died whilst not being told of DES’s harm and needed care. I worry nowadays that mothers are aging, and so the daughters and sons could become stranded without confirmation that DES was prescribed and dutifully taken.

On top of everything, uncertainties add to my worries—cancer and health risks as our daughters and sons get older. Then there’s the health of our grandchildren and future generations.

Over decades I have watched inaction by Australian health authorities in addressing this drug disaster. I am aghast at how our matters have been looked upon with blatant disregard. I want to see justice legally and health-wise for Australians, and for all who have suffered and continue to suffer from effects of DES, the majority of them unknowingly. And I want to see justice done before I die.

DES VOICE

LETTERS TO THE EDITOR

• Regarding articles in VOICE Issue 141 •

As a physician for the past 25 years, I was shocked at the implications made in your article “Cutting Drug Company Influence Over Doctors May Be Tougher Than Expected.” Your charge that gifts, trips, lavish meals and other monetary incentives influence our prescribing habits could not be farther from the truth.

All the treatments we use, whether medical or surgical, have been through rigorous trials and FDA approval. A physician’s goal is to cure his/her patient with the most current and effective treatment available. Your accusation that our prescribing habits can be bought would be laughable if

it were not a direct and libelous attack on our character.

If you have specific instances where “bad apples” have done so, then say so. Please don’t slander an honorable profession. After all, your health and mine have benefited from the tireless hours of study and self sacrifice that we as physicians have made.

My wife is a DES Daughter and was equally angered by your article. We both suggest you stick to your charter and search for answers regarding the health problems of the DES-exposed.

*Sincerely,
David Frey M.D.*

I just wanted to tell you how much I appreciated the article by Cecelia Volk in the current issue of the VOICE. The HPV problem is one I deal with also and have never gotten a straight answer from my doctors about why I sometimes test positive and sometimes not. Or whether there is a connection to DES or if DES has an affect on this problem.

Please tell Cecelia that sharing her personal story was very beneficial to me and I’m sure to others, too. And thank you again for doing all this great work!

Marlene

DES VOICE

Infertility Now An Emerging Public Health Priority

By Fran Howell

The large number of American DES Daughters and DES Sons who struggled with infertility had for the most part either succeeded in growing their families, or made other plans when a growing awareness of the problem was emerging at the Centers for Disease Control and Prevention in 2007.

Seven years later, in 2014 a working group released its National Public Health Action Plan for Detection, Prevention, and Management of Infertility. Described as a call for action, it is, “A coordinated and multidisciplinary approach to address infertility, from primary prevention to treatment and support.”

This comprehensive 26-page publication addresses the public health importance of infertility, which is described as being unable to conceive for at least a year.

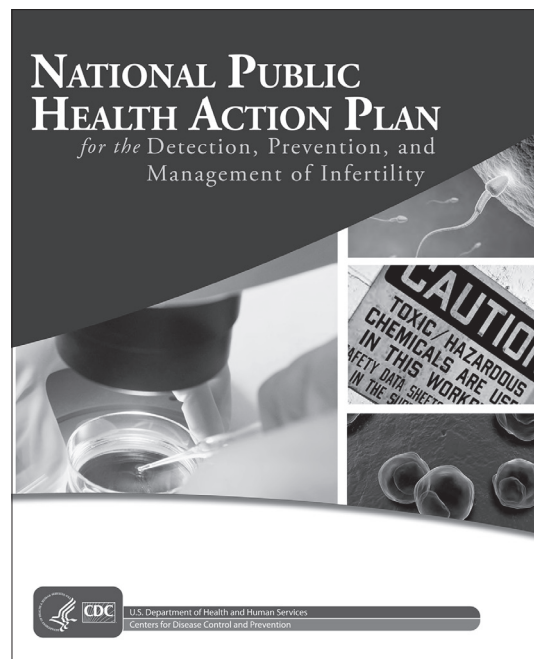
Examining causes of infertility, the writers of the National Action Plan list a myriad of factors including, “Genetic abnormalities, aging, acute and chronic diseases, treatments for certain conditions, behavioral factors, and exposure to environmental, occupational, and infectious agents.” **The DES exposed fit squarely into the environmental exposures category and the report specifies that a better understanding of harms caused by prenatal exposures is crucial.**

They also point to the need for more studies into such conditions as polycystic ovary syndrome, menstrual cycle defects, endometriosis, uterine fibroids, thyroid issues, autoimmune conditions and testicular disorders as they relate to infertility.

Other areas of research called for in the plan include establishing biomarkers, determining the predictors of early depletion of the ovarian reserve and learning about the effects of age on semen quality. Given special attention is identifying the role endocrine disrupting-compounds play in our nation’s health. The terrible DES experience first brought that concern to the forefront in regard to fertility.

Failure to achieve pregnancy can be devastating, with psychological stress, anxiety and depression all swirled in with self-esteem and anger issues. Treatment has its own associations with potential health problems for women, men and the resulting children.

Among the risks: some (but not all) research suggests that infertility treatments may be associated with an increased risk of gynecologic cancers. Infertility treatments have increased the rate of multiple births, which put both mother and infants at higher risk of adverse health outcomes. Even singleton births resulting from treat-



ment are associated with increased risk of low birth weight.

Identifying infertility as a national public health priority comes at a time when concerns are growing of possible DES Grandchild fertility issues. Hopefully, goals set forth can be met for promoting healthy pregnancy outcomes from treating infertility, and improving the safety and efficacy of these treatments.

The action plan report makes for interesting reading, especially among those whose lives have been, or might be, touched by infertility.

<http://www.cdc.gov/reproductivehealth/Infertility/Whitepaper-PG1.htm> **DES VOICE**

Osteoporosis

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associated with a 54% reduction in the incidence of osteoporosis among unexposed women participants in the study, while only a 33% reduction was seen in the DES Daughter group that began menstruating early.

While estrogen produced in the body seems to be protective against osteoporosis for most women, that

protection appears to be weakened for DES Daughters. In general, human studies do not show DES Daughters having a higher incidence of osteoporosis, indicating that other factors may be at play in its development.

The finding that prenatal DES exposure may *interfere* with the usual osteoporosis protection offered by a woman’s natural estrogen production through her lifetime is new. Research-

ers concede they don’t yet understand the mechanism for why it occurs.

One thought is that skeletal growth could be programmed in the womb, leaving a fetus more susceptible to osteoporosis, because of prenatal DES exposure. This hypothesis provides additional support for the growing understanding that hormonal exposures before birth are linked to the development of adult onset diseases. **DES VOICE**

Breast Cancer In DES Daughters With A Potential Risk For Granddaughters and Great-Granddaughters

“Maternal exposure to diethylstilbestrol during pregnancy and increased breast cancer risk in daughters,” Leena Hilakivi-Clarke. *Breast Cancer Research*, 2014, 16:208.

Reviewed by Kari Christianson

The two-fold increased risk for breast cancer in DES Daughters has been well documented in research involving women and animal models. But “how” breast cancer develops and the mechanisms that cause it are not fully understood. Studies into the risks for DES Daughters and subsequent generations may offer a unique opportunity to learn more about breast cancer.

This scientific review of DES breast cancer research focuses on mechanisms that have been suggested as causes for the increased risk. Animal studies about DES-caused changes during fetal development and puberty are compared side-by-side, adding to understanding the DES connection to epigenetic changes. In contrast to gene mutations that involve non-reversible changes in our genetic material, epigenetic changes mean that a gene is locked when it should be open, or it is open when it should be locked. An inappropriately locked gene can be opened by drugs called HDAC and DNMT inhibitors.

The effect of DES on the fetal mammary gland suggests long-lasting changes in development of the glands. DES exposure caused the development of more than the normal number of mammary terminal end buds, which are primary targets for breast cancer susceptibility both in animals that are used to study DES on breast cancer risk and in the human breast.

As researcher Leena Hilakivi-Clarke, Ph.D., from Georgetown

University states, “It is thus possible that one of the mechanisms causing an increase in mammary cancer risk in DES-offspring is an increase in the number of targets for malignant transformation.” The increase in terminal end buds in the animal model “might be modeling high mammographic density in women.” Dense breasts are strongly linked to an increased breast cancer risk.

Hilakivi-Clarke is a professor of oncology who studies the role of estrogens in breast cancer. Trans-generational effects of maternal estrogenic exposures during pregnancy on offspring’s breast cancer risk is a focus in her research, which includes examining the alterations causing an increase in breast cancer risk among daughters, granddaughters and great granddaughters.


Like many of the adverse outcomes due to prenatal DES exposure, not all DES Daughters or Sons have the same health or reproductive tract changes. However, in most cases the same types of adverse changes due to prenatal DES exposure are found in all international DES research study populations. But this has not been the case in the rates of DES Daughter breast cancer to date. International DES Daughter studies have not reproduced the National Cancer Institute (NCI) DES Follow-up Study finding of twice the risk of developing breast cancer.

Hilakivi-Clarke points out that differences in breast cancer risk findings in DES Daughters studies from other countries may be the result of a lower level of prenatal DES exposure and a younger cohort population than in the U.S. She states, “Once the European daughters reach the age when breast cancer is more commonly detected,

they too are likely to exhibit a significant increase in breast cancer risk.”

Breast cancer due to DES exposure needs more study. Hilakivi-Clarke points out, “The increase in risk may not be limited to the DES-exposed daughters, but could also increase breast cancer risk in granddaughters and great granddaughters.” She explains that prenatal DES exposure appears to reprogram the epigenome of both germ cells and mammary cells causing a permanent biochemical footprint in the DES Daughter generation that may be inherited by subsequent generations. Animal research has long pointed to this possibility.

“The increase in risk may not be limited to the DES-exposed daughters, but could also increase breast cancer risk in granddaughters and great granddaughters.”

Hilakivi-Clarke suggests an urgent research effort is needed to stop the inheritance cycle that seems to put DES Granddaughters and Great-Granddaughters at increased risk for breast cancer. She views this multiple generation risk potential as an opportunity to study the ability of HDAC and DNMT inhibitors in reversing epigenetic changes that cause an increase in breast cancer risk. “Some drugs that are used to treat migraine or hypertension also are HDAC and DNMT inhibitors and are well-tolerated by healthy individuals”, she says. “These drugs are already used in clinical trials to treat breast and other cancers that fail to respond to standard therapy.” 

Seven Tips To Reduce Exposure To Likely Breast Carcinogens

We can't change our prenatal or generational exposure to DES, but there are plenty of things we can do to reduce exposure to common chemicals that have been linked to a higher breast cancer risk. Our friends at Silent Spring Institute have put together "Seven Tips" in an easy to follow format. They've given us permission to share it here.

The Silent Spring Institute is celebrating its 20th anniversary this year. Their research has identified problems with many toxins in our environment and works to prevent future health disasters. DES Action USA congratulates Silent Spring Institute for being a strong voice for the environment and women's health, and we thank them for their continuing dedication to public education.

A wide variety of everyday chemicals cause mammary tumors in animals. That's worrisome evidence the chemicals may increase breast cancer risk. While scientists continue to learn more about how these chemicals affect humans, there is enough information to reduce our exposures now.

- Lessen exposure to fumes from gasoline and to exhaust from diesel or other fuel combustion. Support anti-idling and fuel efficiency regulations.
- Use a ventilation fan when you cook, and limit consumption of burned or charred food.
- Find a dry-cleaner who doesn't use PERC or other solvents; ask for "wet cleaning."
- Use a solid carbon block drinking water filter. Help keep your drinking water clean by protecting source waters.
- Avoid stain-resistant rugs, furniture and fabrics. Tell retailers and manufacturers you don't want PFCs in your home—or in the Arctic—where these persistent chemicals build up.
- Ask for furniture that doesn't contain flame retardants, including in the foam. If flame retardant free foam isn't available, choose furniture made from naturally flame-resistant fabrics and padding such as wool, hemp, polyester, latex, down, or leather. Choose rug pads made from felt, jute, or rubber rather than foam.
- Since chemicals accumulate in house dust, remove shoes at the door, vacuum with a HEPA filter, and clean with a damp rag or mop.



None of us can prevent breast cancer alone. Organizations like Safer Chemicals, Healthy Families can help you take national action. Learn more at www.saferchemicals.org.

Silent Spring Institute — www.silentspring.org/biomarkers

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See It For Yourself!

Our New Website Is Well Worth A Visit — www.desaction.org

The DES Action USA website has undergone a facelift; we're sure you'll like its fresh and updated look.

You'll also be pleased to find it's full of new links to DES research articles, historical documents and other interesting reading.

The website is crafted to provide easy access to information specific for the needs of the DES-exposed, those who think they might be, and family and friends who want to know more about DES.

Our newly renovated site is easy to navigate and is filled with accurate DES material available 24-hours a day from a source you trust.

Without a doubt you now have your new *Go To Resource* for all things DES.

Have a look; explore the site and then **BOOKMARK** it to return again and again. You'll be glad you did!

