

## LET US INTRODUCE OURSELVES

**By Su Robotti, MedShadow  
Foundation President**

MedShadow Foundation has just taken over management of DES Action USA, and I'm both thrilled and nervous about this new reality. Thrilled because of what DES Action has meant in my life: it has given me a community of fellow DES Daughters and DES Sons to share information with and garner support. Nervous because the small staff and board of DES Action have been giants in serving the community and we at MedShadow Foundation need to step into those shoes. We intend to continue the web site, the DES Daughter's Online Support Group listserv and the DES Action VOICE newsletter. Very little will change, because we believe in the mission and work of this strong and successful organization.

On February 1, 2015 MedShadow's staff became DES Action's staff. When you call DES Action's toll free number: 800-337-9288, Kimberly Bliss, our Administrative Manager, will answer. Kimberly will also send out membership mailings and help with the VOICE. Colleen Gardephe is our Content Editor for the full MedShadow Foundation, she decides what topics to cover and what writers to hire. Our Digital Manager Deirdre Wyeth and Julie Livingston on PR round out our staff. I manage the group and write a blog every week.

I invite you to visit MedShadow.org and sign up for our weekly update (in the right-hand column on the front page). We are consumer advocates and our mission is to empower you to do something very simple, have a conversation with your doctor about the short-term and long-term effects



*Top Row (left to right): Kimberly Bliss and Deirdre Wyeth, Seated: Julie Livingston and Su Robotti*

of the medicines prescribed for you.

MedShadow can help. We gather information on the side effects and long-term effects of drugs to help you understand all the benefits and risks before agreeing to take any prescription. The information is posted on our website. We also have a downloadable form to take with you to the doctor's

office, titled: "Questions Your Health-care Provider Will Welcome." Find the link to this useful tool in the right column of our home page.

MedShadow Foundation was started because I'm a DES Daughter. Two years ago I was at a moment in my life when I'd left my job, sent my child to college and realized I had time to do what I wanted. I thought, if I could do one thing, what would it be? The damage that DES has caused to millions of people sprang to mind, and I realized: I never want another DES tragedy. I don't want anyone to be as damaged by a medicine as millions of us were. That concern was the catalyst behind my creation of MedShadow Foundation and my desire now to pour my passion and energy into the work of DES Action USA.

Please write and call us with suggestions and encouragement. We want to continue the great legacy of DES Action, and your involvement will make the difference.

## A Gift For You!

### Here's A Token of Appreciation To Our Loyal Members

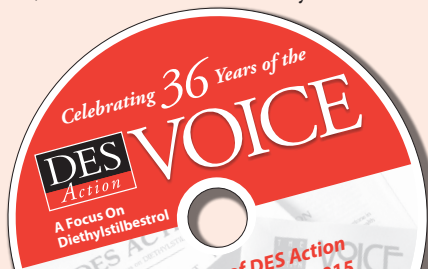
One of the most popular benefits of DES Action USA membership is in your hands right now. Our VOICE newsletter was first published in January 1979 and has been printed continuously, four times a year, ever since. That's 36 years of

covering the struggles and successes of the DES movement. One hundred and forty-three issues!

**The VOICE documents our organization's proud history, while sharing DES information of interest to us all. So, as a thank you to our loyal members, we compiled the DES Action VOICE newsletter archives on a searchable CD-ROM.**

Reading about DES research in the VOICE keeps us current on accurate

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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.

- Excitement was generated by a haunting new DES song created by a DES Grandson with lyrics from a poem penned by his mother, a DES Daughter and DES Action member. Take a listen: <https://www.youtube.com/watch?v=l5KQHFQHJMs&feature=youtu.be>
- Lots of 'likes' for new FDA rule requiring risks be clearly identified so women can make informed choices on taking drugs while pregnant. That wasn't offered to our Mothers who were told DES was safe for their children. Let's hope this works to protect others!
- Concerns were raised about handling thermal paper store receipts after using hand sanitizer or skin lotion. The creams contain chemicals to enhance transport of the

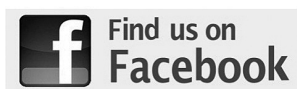
product through the skin. But handling receipts made with BPA delivers high doses of the dangerous endocrine disruptor into our bodies, too.

## 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.



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](mailto: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.



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# Celebrating Successes and Empowering Members

**By Fran Howell**  
**DES Action USA Executive Director**

I've had the most amazing 10 years imaginable and am incredibly grateful. Together we've worked as a team, with your support allowing DES Action's activists to take the lead on an issue that affects us all.

This is a terrific opportunity to celebrate our successes. Over the years your organization has been the strongest advocate for continued Congressional funding for DES research and education. Our collective voices challenge drug companies that focus on profits by pushing 'prevention through pills'—whether safe and effective or not.

There is a photo of DES Action Co-Founder Pat Cody here in the office that continues to inspire me. Pat was the gifted leader who spoke truth to power, earned the hard-to-come-by respect of



researchers, and refused to let the matter of DES be swept under the rug. After this tenacious DES Mother was finally able to get her daughter appropriate health care, she wanted others around the country to have access to it as well. That drove Pat's work. I learned from the best!

Activists, many using the DES experience as a cautionary tale, are leading the call for better regulation of endocrine

disruptors. If that means we've all learned from the DES tragedy, and the research provided by rigorous scientific investigation of it, then I'm encouraged that perhaps similar experiences can be averted—one positive out of so much negative.

My intent in communicating with each DES Action USA member has been to leave you better informed and feeling valued. You play an important part in helping make positive things happen for us all. Advocating for the DES community is a team effort and I'm thrilled it will continue as an important part of the work of MedShadow Foundation. We are in excellent hands.

I wish each of you good health as we stay connected to an organization that means so much to us. As for me, I've got my National Park Service Senior Pass, so I'll be exploring the national park system. Please wave when you see me on the trails!

## Making Sure Our Injuries Are Not Forgotten

**By Kari Christianson**  
**DES Action USA Program Director**

Fran and I have been spending quality time with our members for the past ten years as DES Action's staff. But our connections with this organization and with all of you go back for years, and in my case, for decades. DES Action has been part of my life for 35 years.

It was during my very first meeting with other DES Daughters in early 1980, that the difference between a disease and a toxic exposure became crystal clear to me—we are not sick; DES injured us. And, not only was DES unsafe, but also DES was ineffective for preventing miscarriages. An activist was born! Of course, our injuries may manifest as a disease like cancer or affect fertility. And while there may be treatments for cancer and interventions to assist with fertility, there is no cure for DES exposure.

Those of us who are DES-exposed are not looking for a pharmaceutical fix; we understand that's not possible. What we want—and need—is additional study



of how DES continues to affect DES Daughters, DES Sons and DES Grandchildren. Additionally, we are very aware that there yet may be adverse health consequences that could affect generations to come. This work continues for DES Action and for all of us.

One of DES Action's goals has been to make sure that our injuries are not forgotten. DES exposure remains the warning event about how a hormonally active drug harms humans, potentially for generations. If the sobering lessons from DES exposure are not learned, there is little hope that future pharma-

ceutical disasters can be prevented.

I've often said that I can't "retire" from being a DES Daughter, any more than I can be "cured" of being DES-exposed. But I can step back from staff work and return to my volunteer role with DES Action. I will continue to represent DES Action and share our members' experiences with the research community, particularly the National Cancer Institute DES Follow-up Study and the National Institute of Environmental Health Sciences Partners. I'm looking forward to spending more time with my husband, who retired eight years ago, and our growing family of grandnieces and grandnephews. And, yes, there will be more time for exploring Minnesota's wineries.

Thanks to all the members of DES Action for your friendship and support throughout my years with this organization. It has been a privilege to work with all of you and with those members who have served with dedication on the board of directors. I look forward to the future of DES Action USA and the work that we continue together.



# YOUR VOICES

*Reactions came in swiftly after DES Action USA's transition announcement was made public. It's been heartwarming here in the office to read these member comments, which are deeply appreciated. Now we join you in looking to the future, as DES Action segues into its new phase of activism.*

Congratulations! This is a significant step for DES Action. Kudos! My very best to one and all, you have always been, and I am sure you will continue to be the voice of DES Daughters, Sons and Grandchildren. With great admiration for your work and commitment,

— Nora

Thanks Fran and sorry to see you retire from DES. You did a great job advocating for us.

— Nancy

Congrats to Fran and Kari! They have both been part of this wonderful org for many years. Even before they were officially "staff" they were involved as volunteers. We are lucky to have had them as our advocates!

That said, I am excited to see where we go as part of MedShadow. We will always be the "canary in the coal mine" and I'm hopeful that with the broader lens at MedShadow maybe DES will garner additional attention and continue to remind lawmakers, the public, etc., that we should proceed with caution when it comes to "new and improved drugs."

—Jill

I cannot thank you each and both enough for the tremendous guidance, support, comfort and warmth you have shown us throughout your many years at the helm. I honestly don't know where I would have turned if not for DES Action. As I think back over these many years I recall the exact day I became aware of this group – it was through Candy Tedeschi, NP, who though not "one of us," is a tireless advocate for us all. You will be a tough act to follow, but I trust you are "leaving us" in good hands. I wish you both the very best in retirement! You greatly deserve it and then some.

—Joan

Take a bow, ladies. We give you a standing ovation.

—Nancy

Thanks, Fran and Kari, for leading us all this time! You have built up a wonderful organization and such a terrific listserv for DES Daughters. It's all been important to me in many ways! We'll miss you so much. Also I'm looking ahead with anticipation to Su Robotti's leadership for us at Medshadow. Can't thank you enough!

—Lois

So happy and grateful that Fran and Kari are going to be able to relax and enjoy retirement! How exciting for you both! But I must admit I am excited about the future of DES Action, too. We are going to be in the hands of an amazing group that seems to care about our cause and is actively interested in perpetuating DES information, resources and action! Su and her team sound energetic and excited to embrace all we do and take it into the future by raising DES awareness and giving our cause an even bigger voice. I'm thankful for this new opportunity because, from what I can tell, DES Action will continue with its vital work.

—Jackie

Fran and Kari, thank you so much for all you have done on behalf of those affected by DES exposure. I have admired the professional and dignified manner in which you represent DES Action, as well as the caring, personal touch that you offer to those facing the dire effects caused by this drug.

I wish you both a bright, healthy and happy future. Congratulations on your retirements.

*With gratitude,*  
Carol

## A Gift For You

*continued from page 1*

and timely information that's hard to find anywhere else. You trust what you see here because it comes from scientifically valid resources. DES Action's valuable connection with researchers has allowed us to factually communicate complicated study results, in language we can all understand.

Another focus made clear in reading our newsletters is a push to spread

DES education. You may remember wearing an "Ask Your Mother" button.

**The DES Action VOICE is written for, by and about our community – the thread that holds us all together. As you scroll through the archives you'll notice compelling and heart-wrenching personal stories. We learn from our shared experiences and gain strength and comfort in realizing we are not alone in dealing with the scourges**

## of the DES Tragedy.

If you don't have a computer, maybe there's a family member or friend who can help. Perhaps they should know about DES anyway. We're always trying to spread the word.

In a few months you'll receive VOICE 144, because publication continues. There will be many more issues ahead, so you can continue staying current on DES matters of importance to us all.

# THE DES STORY

## A Public Health Disaster—A Personal Tragedy

The DES story needs to be told. It is a story that raises fundamental questions about health care in America, from the testing and manufacture of drugs to the doctor-patient relationship and the sometime disastrous effects of overzealous medicine.

The DES story is a story of medical faith in a poorly tested product, of patients' faith in their doctors, and of those whose lives have been changed as a result.

The DES story is a story of suffering and, sometimes, death from disease caused by a medication meant to produce life. It is a story of unsuspecting mothers, inadequately informed doctors, and in some cases unscrupulous drug manufacturers—all adding up to personal heartbreak for many Americans.

It is also a story of precedent-setting legal battles between individual consumers and giant pharmaceutical companies. These are battles that, though

weighted against the consumer, nevertheless upheld the rights of all consumers to be prescribed adequately tested and responsibly marketed drugs.

Lastly, the DES story is a family story. Mothers and their children coming to terms with health problems resulting from a drug given during pregnancy, ironically one thought to create “bigger and stronger” babies.

There are thousands of people who still do not know that their health may be in jeopardy because of a drug prescribed years ago to their mothers. The story of DES is made up of all the individual stories—of a young woman who had no idea she was a DES Daughter until her diagnosis of cancer of the vagina; of a couple who dreams of parenthood are shattered by miscarriage after miscarriage; of a DES Daughter who is facing breast cancer surgery; of a DES Son who wonders if his daughters could be affected because of the drug his mother was given during the

pregnancy with him.

### Here's why the DES story needs to be told today:

Scientists continue to uncover new and startling health problems linked to DES exposure. Recent studies suggest a higher incidence of breast cancer, rheumatoid arthritis, osteoporosis, fractures, cardio-vascular disease, as well as concern about the third generation—the children of DES Daughters and DES Sons. That's why our government continues to recognize the need for additional DES research about the long-term and generational effects.

DES research provides a window for understanding the role endocrine disruptors play in human health. The connections made between prenatal DES exposure and adult onset of disease helps scientists continue to unravel the mysteries of how environmental exposures, like prenatal exposure to DES, affect our health and fertility.

## Zeroing In On How DES Raises Cancer Risks

S Sophia Harlid, et al. “Fetal exposure to diethylstilbestrol and DNA methylation in adult women.” [abstract]. In: Proceedings of the 104th Annual Meeting of the American Association for Cancer Research; 2013 Apr 6-10; Washington, DC. Philadelphia (PA): AACR; Cancer Res 2013;73(8 Suppl):Abstract nr 3643. doi:10.1158/1538-7445.AM2013-3643

### By Fran Howell

We know DES Daughters are at increased risk for a specific vaginal/cervical type of cancer and also breast cancer. Now we are getting closer to understanding why. This study examines the mechanism for how prenatal DES exposure causes harm.

Animal studies have been zeroing in on a process by which certain genes work, or in the case of DES-exposed

offspring, don't work properly. These genes are not mutated, but rather, despite their normal programming they fail to act in the ways they should. Something, and in this case it's suspected to be DES, causes things to go wrong. Genes that should remain active are turned off, despite their genetic code, or DNA, while others, that shouldn't be active, are turned on.

We depend on our genes to work properly throughout our lives. For example, some are designed to turn-on in adulthood to provide protection against breast cancer. If the process is altered, it's likely the cancer risk is increased.

This field of study into how the function of genes is changed by specific exposures is known as epigenetics. The actual process of turning individual genes off and on is called methylation. While already identified in animals, this is one of the first investigations into how

methylation may work in humans.

Selected from participants in the National Institute of Environmental Health Sciences (NIEHS) Sister Study was a group of 100 DES Daughters and 100 unexposed women. Their blood was analyzed to look for evidence of very specific methylation changes. Differences were found between the exposed and unexposed women, with lower methylation levels in DES Daughters, however the numbers were not statistically significant.

Still, the researchers came away clearly observing methylation changes in blood several decades after prenatal DES exposure. With that observation they urge further study into epigenetic impacts of DES, perhaps using samples from uterine or vaginal tissue to provide stronger verification of how prenatal exposure to DES can increase cancer risks in adulthood.

We are pleased to share this review of an exciting year, full of interesting DES research findings, a major communications upgrade and carefully considered development of plans for the future.

First up is our major overhaul of the DES Action USA website ([www.desaction.org](http://www.desaction.org)). If you haven't visited in awhile, we urge you to have a look. Check out the DES Timeline (from the About DES dropdown-menu) where you can find fascinating documents relating to the history of the DES experience. Other pages provide the most accurate DES information on the web. Our new website is a DES resource you can trust!

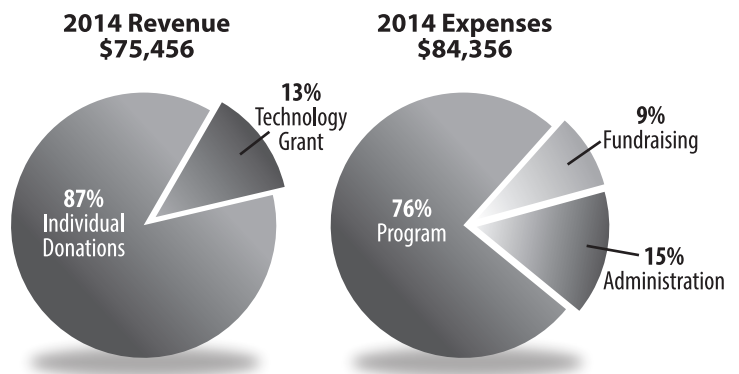
Perhaps the most dramatic research news from last fiscal year is the start of a search to identify a **biomarker** for DES. The question is whether a blood test can someday confirm prenatal DES exposure. Researchers with the NCI DES Follow-up Study are optimistic that they will succeed. Sixty participants were identified, 30 known to be DES-exposed with a matched set of 30 others who are not. The researchers will look for biological differences, something they couldn't do earlier because recent advances in science finally provided needed investigational tools. Anticipation is high that a DES biomarker can be identified in the near future.

**Bone issues** relating to DES Daughters and Sons came under scrutiny this year in two separate studies. A team of researchers wanted to know if prenatal DES exposure interfered with bone, cartilage and disc growth in mice. They found that it does. Male and female adult offspring of pregnant mice exposed to DES showed significant musculoskeletal effects, particularly a weakening of lumbar disc bone growth. Meanwhile, another study looked at bone disease from a different perspective. They investigated the protective effect of natural estrogen produced during the years a woman menstruates. The more years of having periods the

higher the protection afforded against osteoporosis. However, that protection appears weaker for DES Daughters, compared with unexposed women. Research on this will continue.

Somewhat alarming to DES Daughters during this year was news that the FDA approved an **alternative for Pap tests**. The new DNA test checks for HPV, which is the virus causing most cervical cancers. But this new screening will not find clear cell adenocarcinoma, the specific type of cervical cancer of concern to DES Daughters. The good news is that experts don't think Pap smears and pelvic exams are going away any time soon. They predict that women may be given the option of either HPV or Pap/pelvic screening. In that case, DES Daughters would be wise to continue with their annual Pap/pelvic exams.

For the third year in a row DES Action USA was named a Top-Rated Nonprofit on the GuideStar website! This designation recognizes our strong dedication to the mission of identifying, educating, empowering and advocating for DES-exposed individuals. It's embedded into every fiber of what we do. Throughout the months of transition planning this year, our mission was at the forefront of discussions. DES Action is well situated to move seamlessly into the future.



*Board designated net assets from reserve funds covered the difference between revenue and expenses in the fiscal year.*

# 'Pink Viagra'? Why We Shouldn't Rush to 'Fix' Women's Bodies

*The Food and Drug Administration sought input about a condition called "Female Sexual Dysfunction." This is a fairly new term for low libido in women and has not been recognized by the American Psychiatric Association. DES Action USA responded with a letter to the FDA that warns against approving drugs until they are known to be safe and effective for women, even if drugs for treating similar conditions in men have already been approved.*



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*Serving the DES-exposed community since 1978*

Dear FDA Reader:

Thank you for the opportunity to provide written comments for the October 27, 2014, Patient-Focused Drug Development meeting on Female Sexual Dysfunction.

DES Action USA advocates for individuals who were prenatally and generationally exposed to diethylstilbestrol (DES), an ineffective and harmful non-steroidal estrogen given to millions of pregnant women in the U.S. and around the world with the erroneous idea that it prevented miscarriage. Their prenatally DES-exposed daughters have much higher rates of reproductive tract problems, including ectopic pregnancies, miscarriages, infertility and cancer. And this drug disaster may continue to harm future generations.

Because several drugs have been approved for male sexual dysfunction, groups have asked whether the FDA is holding women's sexual satisfaction to a different standard. As a population already harmed by a FDA-approved drug, we wonder if political and media attention is the reason for considering and reconsidering drugs for any female health or disorder issue, rather than attention to safety and efficacy.

The gender equity argument ignores the real safety difference between any drug under consideration for female sexual disorder and the drugs approved for men. All but one of the drugs approved for men are taken on an as-needed basis, whereas a drug for women, like flibanserin, is a central nervous system serotonergic agent with effects on adrenaline and dopamine in the brain and requires chronic—daily, long-term—administration. This raises toxicological concerns that make

it appropriate for the FDA to subject this drug or any similar drug to elevated safety scrutiny. Adverse events reports and dropout rates in the trials rightly require serious consideration.

Hypoactive sexual desire disorder is no longer listed in the DSM-5 (5th edition approved by the American Psychiatric Association in May 2013). Rigorous DSM-5 processes were unable to support a distinction between sexual desire and arousal disorders for women; the new terminology, "female sexual interest/arousal disorder," offers revised criteria for making a diagnosis.

DES Action's online community of DES Daughters has shared information about non-drug hormone-free alternatives and natural remedies that effectively deal with vaginal dryness. And it has been the sharing of our on-going health and sexuality experiences that itself is a remedy. By learning what others are experiencing, we learn about ourselves, what is common, what is normal, and what we can do to relieve symptoms of vaginal dryness safely and inexpensively without pharmaceutical intervention.

No one, particularly the FDA, should be in a rush to "fix" women's bodies via drugs. DES Daughters are living proof that good intentions and poor research lead to disaster, potentially for generations to come.

Sincerely,

A handwritten signature in black ink that reads "Kari Christianson". The signature is written in a cursive, flowing style.

Kari Christianson  
Program Director  
DES Action USA



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so we can easily  
stay in touch.

## Questioning or Pestering Your Doctor?

*We are sharing, with permission, this blog written by DES Action USA  
Executive Director **Fran Howell** that was posted on [www.medshadow.org](http://www.medshadow.org)*

Ever feel like you're bothering your doctor with too many questions?

I know the importance of fully understanding DES health risks. At DES Action we work at empowering individuals to be informed medical care consumers. If you don't know the short and long-term risks of a drug you are prescribed, ask.

A member recently shared with me that she left her doctor's office after a visit without having all the answers she needed: "I guess I just wanted her to explain it to me, without my having to bug her with a bunch of questions. I don't want to become a pain-in-the-neck patient who asks a bunch of questions. She is very nice and very competent, but I just wish she would explain to me more what is happening in my body."

This made me think immediately

about what respected DES health care provider Candy Tedeschi, told us a few years back:

"Now for my soapbox speech: I am a firm believer in women knowing what is going on in their bodies—ask questions, ask for copies of your records if needed, but above all else, understand what is going on with yourself. Ask questions until you understand. I know time is often a problem when you are seeing your health care provider, but this is your body and you need to know what's happening. How can you make health care decisions if you don't understand? Ask for the medical term for your particular condition, and a definition. (Soapbox closed.)"

What Tedeschi said has empowered me to ask questions and thor-

oughly understand what's going on in my body before I leave the doctor's office. I hope it does the same for all of our members—and everyone reading this blog, too.

You have legitimate concerns that need answers. Asking questions in this context is not impolite. You are paying a professional for information. Going in with a list often helps.

If you didn't get all of your questions answered during your visit you might want to consider emailing or calling the doctor for clarification.

Know what is happening in your body. During your office visit don't hesitate to bring up all health questions you may have. Be specific and don't worry about asking too many. Be honest too. Candy Tedeschi would want nothing less.