

The logo for DES Action is centered on the page. It consists of a black rectangular background. The word "DES" is written in large, white, serif capital letters across the top half of the black rectangle. Below "DES", the word "Action" is written in a white, cursive script font across the bottom half of the black rectangle. The entire logo is set against a light gray horizontal band that spans the width of the black rectangle.

# DES *Action*

ANNUAL REPORT 2012

*This year goes down in the record books for all the positive things of interest that happened in the DES community. In this review you'll see a wide spectrum of fronts covered: research, legal and historical. It was an especially busy year!*

*DES Action USA has been an advocate member of the Steering Committee of the National Cancer Institute (NCI) DES Follow-up Study for over 20 years.*

This year, as the NCI has done at least every five years, study participants received a survey to fill out and return with an update of their health experiences. What a huge impact this has for all of us! This peer-reviewed, journal published research is the foundation for our understanding of the harm caused by prenatal DES exposure.

The authority of this study comes from following the health of the same DES-exposed women and men, and matched unexposed female and male control groups, over decades. The DES community relies on this research to understand our own health and reproductive experiences. But even more importantly, the findings are highly regarded by medical experts.

That was made abundantly clear when in late 2011 the *New England Journal of Medicine* published an important article by the NCI researchers listing 12 adverse health affects for DES Daughters caused by prenatal exposure. Throughout the year we have helped DES Daughters advocate for the health screenings they need by providing them with this article, along with other useful information to share with their doctors. This empowers the DES exposed to advocate for the appropriate medical care. We've seen this year how much more willing doctors are to pay attention to DES research information when it comes from a respected source and is delivered directly by a patient. Contact DES Action ([info@desaction.org](mailto:info@desaction.org) or 800-337-9288) for a copy of the information that helps educate doctors.

While the NCI DES Follow-up Study is a closed research project not looking for new participants at this time, DES Action embarked on its own type of study in 2012.



## DES Health History Survey

For the first time since the 1980s DES Action conducted a DES Health History Survey, giving DES-exposed individuals an opportunity to share their health experiences. This is an anecdotal study, meaning proof of exposure was not required to participate. More than a thousand questionnaires were returned from the U.S., and also from around the world.



The last time we did a similar survey the results were helpful in focusing researcher attention on reproductive issues, specifically infertility in DES Daughters. Deborah Wingard, Ph.D., an epidemiologist at the University of California San Diego, is analyzing the current survey responses. She is comparing results with government statistics to see if any medical issues in the DES community show up at a higher rate than in the general population. This research project, begun in 2012, will be completed in 2013, and you will read about the findings in the *DES Action VOICE*.

## A Year of Interesting Research Results

- One study published this year provided an insight that tells an unsettling story none of us wanted to hear: the cancer risk for clear cell adenocarcinoma (CCA) of the vagina/cervix remains a concern for DES Daughters as they age. This population-based assessment, done by the CDC, suggests an elevated CCA risk for DES Daughters now maturing past menopause.

While we learned in the 1970s of the heightened risk for young DES Daughters, we now must remain on alert for this cancer in older Daughters as well. All the more reason to be certain that health screening guidelines are followed. The proper DES Daughter Pap/pelvic exam should be done annually. Even if unexposed women can skip years between screenings, it is wise that DES Daughters do not miss yearly exams.

Researcher Mary White, Sc.D., who heads the CDC's Epidemiology and Applied Research Branch, analyzed the rate of reported CCA cases in women born during years before DES was widely prescribed, during the years of its use, and also in the years after that, when DES use dropped significantly. What she found was a higher number

of diagnosed CCA cases in women born during the DES years—especially in women aged 40–54—as compared with the number of cases reported in years before, and after, the highest years of DES prescribing. This new information flies in the face of earlier predictions saying an increased CCA risk for DES Daughters passed after age 30.

In their analysis White and her team could find no other reason, except DES use, to explain why the number of CCA cases is highest in women born between 1947 through 1971.

It is important to acknowledge that CCA is a very rare cancer, even among DES Daughters. But in White’s assessment, these findings suggest that, “The large number of women exposed in utero to DES in the United States may still be at special risk for CCA as they grow older.” Hence, the continued insistence that DES Daughters of all ages should continue having annual Pap screenings.

- Another important finding that came out this year confirms the DES link to uterine fibroids. Analysis of information provided by African American participants in the National Institute of Health’s Sister Study shows DES topping the list of early-life exposures associated with early-onset uterine fibroids. This mirrors findings in 2010 from analysis of information provided by white participants. The Sister Study is a long-term research project following 50,000 sisters of women who have had breast cancer.
- Last but not least, an animal study with male DES-exposed and a control group of unexposed male mice shows that researchers can disable estrogen receptors located in seminal vesicles to limit damage caused by DES. These National Institute of Environmental Health Sciences (NIEHS) researchers acknowledge that figuring out how DES interacts in the bodies of male mice and by extension, in DES Sons, doesn’t change what happened to those who were harmed. But they hope their work will someday lead to a way for lowering impacts at the time of exposure. Down the road they envision preventing harm from other environmental estrogen disruptors, such as BPA, as a result of what they learn from studying DES.

## DES Daughters Go To Court

All eyes this year were on Boston Federal Court where a group of DES Daughters with breast cancer filed a

product liability lawsuit against 14 companies that made DES. The women claimed these firms marketed and sold DES even though they knew research studies showed it could cause cancer.

The drug manufacturers tried to stop the litigation with a pre-trial Daubert Hearing. At stake was whether the cases could even go to trial. The drug makers claimed scientific evidence linking DES to breast cancer is flawed.

But Attorney Aaron Levine vigorously disputed that by calling experts who presented evidence showing the link is scientifically rigorous enough to withstand courtroom scrutiny.



This contentious legal drama captivated the DES community in 2012, ending with U.S. Magistrate Judge Marianne Bowler’s ruling that yes, there is enough evidence to take the case to court. What a victory! Had she ruled against the DES Daughters it would have meant an immediate end to these cases and presumably all DES breast cancer lawsuits.

In an effort to avert a full-fledged trial, the judge ordered drug makers to negotiate settlements with the DES Daughter plaintiffs. However, during the spring of 2012 these talks broke down, leading Bowler to schedule the first ever DES breast cancer trial.

In the days before it began, DES Action alerted Associated Press reporter Denise Lavoie, who wrote a nationally syndicated article. This publicity helped spread awareness of the DES link to breast cancer and did nothing to please Eli Lilly, which was selected by Levine to be the sole defendant in the case.

On day one both sides presented opening arguments to the jury. But day two brought a surprise: Eli Lilly finally offered an acceptable damage settlement amount. It was accepted, so the trial came to an abrupt end.

There are still more than 50 other breast cancer cases filed by DES Daughters. Judge Bowler again has ordered negotiations to hammer out settlements and avert trials. It’s now hoped drug companies will come to the table ready to negotiate in good faith. If not, it’s back to court. Count on DES Action to keep you informed as the litigation unfolds.

## DES Pill Bottles Now Part of ACOG Museum

Due to an astute and caring member of DES Action USA, there are now old bottles of diethylstilbestrol on display at the History Museum Library of the American College of Obstetrics and Gynecology (ACOG) in Washington, DC. The pill bottles, with the labels showing manufacture by Eli Lilly, were donated to DES Action USA. But when another member, who works at the Library, heard of the bottles, she suggested they be donated to the museum. We were thrilled to do so. They are now on display to show the important—and negative—place that DES holds in women’s reproductive history. Those DES pill bottles are a visual reminder that the DES tragedy will not and cannot be forgotten.



## What They’re Saying About DES Action USA

Our members are incredibly loyal. Many of you have been with us from the start in 1978, or very near to it. Here’s what Mary Lou told us this year and most likely you can relate:

*I honestly can’t imagine how it would have been all these years without DES Action. I am so grateful for the community, the education, the advocacy, the feeling of empowerment! I’m sure I speak for all members. Thank you again—for everything!*

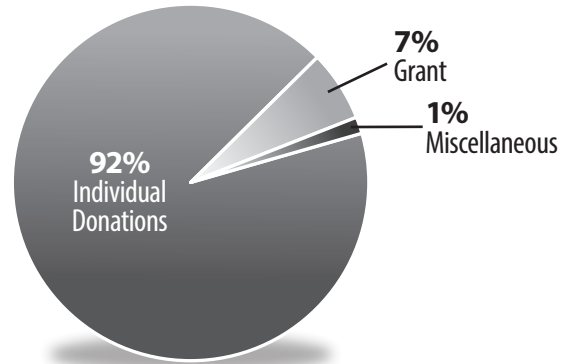
Perhaps the icing on the cake this year came when DES Action USA achieved **Great Nonprofit** status on the GuideStar website—the leading place for donors to find reviews and ratings of nonprofits.



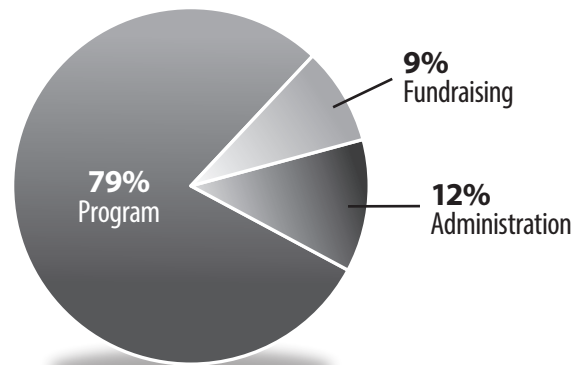
We are enormously honored to attain this classification! It came because of the many positive reviews of our organization with the postings telling of the important impact we’re having for the DES community. They are available at: [www.greatnonprofits.org](http://www.greatnonprofits.org). You’ll be pleased and proud knowing you join so many others who also value DES Action’s work!

In turn, we value the support of all of our members. We couldn’t be the active advocates and strongest voice around for the DES community without your financial support. We give you our sincerest thanks!

## REVENUE \$80,171



## EXPENSES \$81,489



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

## DES Action Board of Directors

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