

DES *Action*

ANNUAL REPORT 2013

We look back on an exciting year full of many positives for the DES community, but with one legal issue we wish had ended differently. All in all, however, definitely a year for which we can all be proud. Let's take a look.

It's worth noting right at the top that DES Action USA celebrated 35 years of Action in 2013!

We honor the tenacious mothers, daughters and health activists who spoke truth to power - demanding answers when concerns about DES could easily have been ignored. Our organization was founded well and remains the strongest advocate for DES research and information.

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One of our members beautifully summed up how she feels about our 3½ decades of work, and we think her words will resonate with you:

"I've been a member of DES Action for more than 30 years. It is hard to put in a few words what this organization has meant to me. I guess I am most grateful that I've had access to clear, straightforward, up to date information every time I was facing another surgery or health challenge. The information has empowered me to be an advocate for myself, sometimes in the face of medical professionals who seemed uninterested or dismissive about my DES exposure. It has also helped me to know that I am not alone."

—Carolyn

DES Health History Survey

With more than 1200 individuals completing surveys about their health experiences, it was fascinating reading results as they unfolded in the VOICE this year. Deborah Wingard, Ph.D., an epidemiologist at the University of California San Diego, analyzed responses that provided some interesting findings.

First, the highest numbers of health conditions reported corresponded with conditions already known or suspected to be associated with DES exposure. This was reassuring because when we held a mirror up to ourselves, the reflection showed research studies are accurately depicting what is happening to the health of those of us in the DES community.

What became apparent from the statistics, however, is that immune system issues still need a closer look. Both asthma and lupus were reported at higher levels in DES Daughters and DES Sons than anticipated.

While anecdotal surveys such as this cannot definitely prove an association, they give guidance as to where

more rigorous research attention should be paid.

We also learned that most reproductive tract issues affecting DES Daughters were **not reported** in large numbers for DES

Granddaughters, including cervical anomalies (hoods, ridges), adenosis and having a T-shaped uterus.

Questions about fertility must wait for another time because the mean age of responding DES Granddaughters was 28 and many have not yet attempted pregnancy.

It also appears too early to draw conclusions regarding possible adverse effects for DES Grandsons. Epidemiologist Wingard suggests that perhaps DES is more likely to have an affect on those directly exposed than those indirectly exposed (the grandchild generation). However, like DES Granddaughters, the mean age for DES Grandsons who responded to the survey was 22 years old, so it's possible the prevalence of some conditions could become apparent over time and should be monitored.

We give thanks to all the DES Action members and friends who shared their health experiences for this important anecdotal survey.

Breast Cancer Litigation

The long, drawn-out legal battle filed by DES Daughters against drug firms that produced DES ended with settlement agreements this year instead of a jury trial.

Just after court proceedings had gotten underway, Eli Lilly abruptly settled with the four DES Daughters in this first breast cancer case. The judge then ordered both sides to negotiate settlements for the remaining plaintiffs. It took months of wrangling until deals were hammered out. They are private and cannot be made public, as is common practice in these situations.

What disappointed many in the way this played out is that drug companies were not forced to admit they did anything wrong. Many in the DES community were disappointed after hoping for a guilty verdict.

But one DES Daughter plaintiff put a positive spin on the outcome. "I'm glad to have been involved. Now I can put this chapter behind me and move on to educate others facing the health issues DES exposure brought to us."



The case itself actually helped do just that. Perhaps the silver lining is all the news media coverage generated by the DES breast cancer litigation when a national spotlight was focused on the DES issue. The stories served to remind those who knew of their DES exposure that it's part of their health histories and should not be ignored.



The news coverage was also educational and helped others assess their personal medical experiences to discern if perhaps they, too, were exposed to DES before birth. The result was a spike in requests for information about DES that came to our organization, both from the known exposed and the suspected exposed. We were pleased at this opportunity to share accurate DES knowledge with those who should know about it.

DES Action DES DAUGHTER TOOLKIT

It's one thing to heighten public awareness of DES and quite another to educate medical professionals about it. Many stubbornly, and wrongly, dismiss our DES concerns. So DES Action USA embarked on an important initiative this year to help DES Daughters communicate better with their providers.

Our new DES Daughter TOOLKIT pulls together screening guidelines and research results from resources trusted by doctors. This information isn't new and is already available. But the TOOLKIT pulls it all together and packages it in a professional and useful format for doctors to easily read and understand.

Reports from DES Daughters tell us it works incredibly well and medical providers are paying attention.

"I handed the toolkit to my doctor who read it right away. She thanked me and I was comfortable knowing she did my Pap correctly. Now the toolkit is in my file for future visits."

—Fran

Each DES Action USA member received a free DES Daughter TOOLKIT in the Fall VOICE (issue 138). Additional copies are available at two for \$5, which includes shipping. Send a check to DES Action USA, P.O. Box 7296, Jupiter, FL 33468.

Or order online at <http://desaction.org/donate.htm> and specify when ordering that you would like extra DES Daughter TOOLKITS.

On The Research Front

- This is the year when a new study broadened areas of health issues that may affect DES Daughters and DES Sons. Researchers with the National Cancer Institute (NCI) DES Follow-up Study found a higher incidence of diabetes, cardiovascular disease, coronary artery disease, heart attack, hypertension, osteoporosis and bone fractures in the DES-exposed cohort compared with a matched group of unexposed individuals.

Of note is that researchers found that associations between DES and the health issues under study seemed weaker in men compared with women, except in the areas of stroke and osteoporosis. In those two cases the incidence turned up higher in exposed than unexposed men.

Both nationally and internationally researchers are studying the role endocrine disruptors, like DES, may play in human health, particularly regarding cardiovascular disease (CVD). So this study, which suggests an association between DES and CVD, is especially important. This is the first study associating DES exposure with these adverse health effects so further investigation is planned.

- NCI DES Follow-up Study researchers reviewed DES Daughter bra sizes in hopes of explaining the DES link to breast cancer. The thinking is that prenatal DES exposure may cause the development of additional mammary gland cells during gestation.

What they found is that for women with a 34" or higher chest circumference there was no association with DES exposure. However, DES Daughters who were quite lean at age 20 showed an 83% greater prevalence of a C or larger bra cup size. Taking it a step further, those women who were exposed to the highest doses of prenatal DES had the larger bra cup sizes.

Given these results researchers concluded there seems to be a link between DES and greater mammary mass. They suggest this shows a mechanism for the possible association of prenatal exposure and an increased risk for breast cancer.

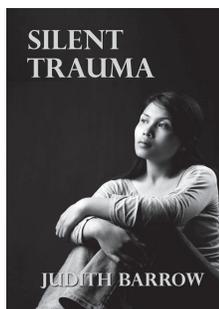
- A separate effort is underway to figure out what causes breast cancer. Blood samples taken in California in the 1960s are being taken out of

storage now to examine environmental links to the disease. This is not a DES specific study but there is a connection. DES Action USA Co-founder Pat Cody was one of the women who participated by giving her blood. She spoke often of her hope those blood samples would someday be used for important research.

Also, many of the scientists working on this new study are researchers who've spent years studying DES. We've stayed in touch with them and hope what they've learned about endocrine disrupting exposures from their work with DES will prove useful now.

New DES Novel Gets it Right

Researchers tell us of harms caused by DES—but *Silent Trauma*, by author Judith Barrow, details emotional harms not visible under a microscope. This meticulously researched fiction-based-on-fact novel pulls back the curtain on wrenching emotional consequences of exposure. Guilt, sadness, depression, and tortured relationships are heartbreakingly familiar, in some part, to many who live with DES. And then comes the strength to survive.



You know the emotions so this book can help you explain them to family and friends. *Silent Trauma* spreads much needed DES awareness with its message that drugs should be more carefully tested and regulated so we can be better assured that the drugs being prescribed are safe.

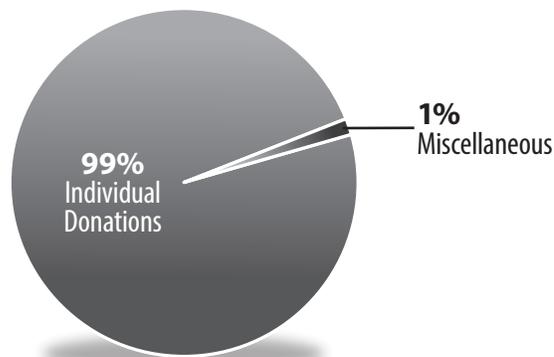
DES Action USA Named a Top Nonprofit!

For the second year in a row DES Action USA earned recognition as a Great Nonprofit on the GuideStar website—the leading place for donors to check reviews and ratings of nonprofits. <http://greatnonprofits.org/org/des-action-national> We don't take this designation for granted and we are glad so many individuals see us this way!

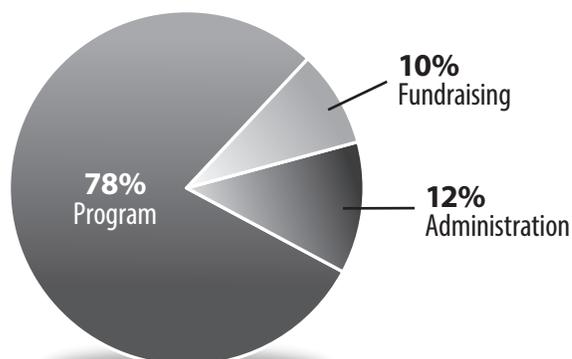


DES Action USA is nothing without our loyal members, with some of you keeping your membership current for decades. We are pleased at how you value our work and we sincerely thank you for making it possible.

REVENUE \$74,633



EXPENSES \$75,855



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

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