

DES *Action*

ANNUAL REPORT 2007

Thirty years ago several small groups from various corners of the U.S. melded together to form a strong and lasting organization. In 1978, little was known about DES health concerns, and few people knew about DES exposure.

So much has changed since then, and yet, important things have stayed the same. DES Action keeps a sharp focus on diethylstilbestrol and the needs of its members.

We are pleased to share with you this operating and fiscal report, which shows strength in both areas.

The old adage certainly holds true, “when something needs to be done, ask a busy person,” or in this case a busy organization. DES Action is keeping busy and meeting new goals.

The year 2007 was a time for updating information resources. Two important ones are our DES Action brochure and the DES Action web site. Both were given new looks and the latest DES information.

Brochure

It wasn't easy compiling everything we now know about exposure into a single pamphlet. It was developed with updated information regarding health effects of exposure — including the recently identified increased breast cancer risk for DES Daughters, the latest on DES Sons issues, and a section on the emerging field of DES Grandchildren research.

Our brochure came together well and has been useful not only for our members, but also for those just learning about DES. We did a mass mailing to members, send batches to doctors who request copies for their patients, and send it out to all who request information. One of our DES Action members works at a mammography center. She wrote to tell us:

“We all love the new brochures. They really spell out the problems with DES and save me lots of explanations!”
— Jenny

Please let us know if you'd like additional copies.

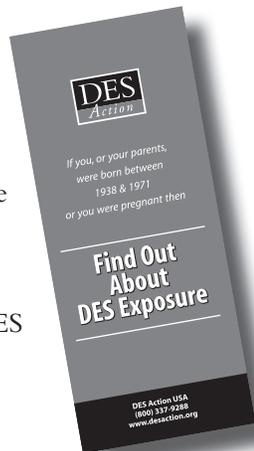
Web Site Redesign

What took perhaps the most time this year was a careful and complete revamping of the DES Action web site (www.desaction.org).

It has people talking. . .

“The web site looks fabulous. It is full of information and easy to use. It is really wonderful.”
— Elizabeth

“The new web site is absolutely fantastic! I especially like the clock counter ticking off the years without an apology from drug makers. What a clever idea. You can really tell how much time and effort you put into this huge project.”
— Sharon



The enormous effort was important since web sites are fast becoming the faces of organizations like ours. We succeeded in developing a site with a clean, professional, yet friendly look that is easy to negotiate and filled with the most accurate and current DES information available anywhere.

A new on-line feature now allows you to make donations and renew your DES Action membership using a credit card. Go to the Join/Donate page where you'll find several options.

If you haven't yet visited our web site, I urge you to do so. It has more valuable DES information compiled in one place than you'll find anywhere else. Because it is easy to update, we keep it filled with the latest on DES research and information you need to know.

Research

We have been hoping that DES-linked health issues do not extend into the DES Grandchild generation. But those hopes began to crumble this year with researcher Linda Titus-Ernstoff's study showing DES Granddaughters are slower than unexposed teens to achieve menstrual regularity. Her findings, published in the *International Journal of Epidemiology*, also hint at infertility problems for these young women. However, Titus-Ernstoff stresses that this is preliminary research and additional studies are needed to follow DES Granddaughters as they age into their reproductive years. When new results come in, you can count on DES Action to let you know about them.

When a 2006 study revealed that DES Daughters over age 40 are at heightened risk for breast cancer, the next question was whether a specific cancer type was involved. In 2007 researcher Pam Larson and her team learned that there is no specific tumor or gene mutation associated with breast cancers in DES Daughters. Their study, published in the journal *Cancer*, found that while no one malignant tumor type is linked to the breast cancers diagnosed in DES Daughters, prenatal exposure may cause increased growth of cells that develop into breast cancer. This leaves DES Daughters vulnerable to various breast malignancies at an earlier age than in unexposed women. Hence, DES Action's strident warnings to DES Daughters to be vigilant about having annual mammograms.



More research results this year brought to light a slightly higher preeclampsia risk for DES Daughters. This pregnancy complication can harm the mother with high blood pressure and fluid retention. If not brought under control, preeclampsia can result in more serious medical conditions. According to the study's lead author, Rebecca Troisi, it is important for DES Daughters to seek high-risk obstetric care when pregnant. Her research validates the experience of DES Daughters who were left wondering whether their exposure might have been responsible for the preeclampsia that developed during their pregnancies.

Another study by Troisi looked into the overall cancer risks for DES Daughters. The assessment, published in the *International Journal of Cancer*, found that the incidence rate for total cancers among DES-exposed woman is comparable to the expected rate for the general population. This finding, however, removes CCA of the vagina/cervix and breast cancer from the equation, because the increased risk for both is already established. What Troisi and her team determined is that at this time, researchers have found no other cancers affecting DES Daughters at a higher rate than in unexposed women, which is clearly great news.

Advocacy

DES Action continues to have a representative on the Steering Committee of the National Cancer Institute DES Follow-up Study. This first-hand contact allows us to meet with researchers on a regular basis, having both formal and informal discussions about the questions DES Action receives from our members.

The National Institute of Environmental Health Sciences Public Interest Partners meets frequently by conference call in addition to regular meetings with the Acting Director of the NIEHS. DES exposure is a primary research link to understanding the consequences of endocrine disruption in the environment. DES Action keeps the attention of researchers directed toward understanding adult health outcomes from prenatal exposure.

DES VOICE *Action*

DES Action's newsletter remains the primary tool for keeping in touch with our members. In addition to reviews of the latest DES research and answers to specific breast screening questions for DES Daughters, the *VOICE* has given members an opportunity to share their DES experiences in the "Your Voice" section.

We include articles that educate us about other estrogens

in the environment and offer suggestions about how we can live healthier lives.

Also, this past year we've followed one of our members, Caitlin McCarthy, who has written a movie script called *Wonder Drug*. We look forward to telling you when this screenplay becomes a movie for all of us to see.

Save the Date

Plans are in the works for DES Action's 30th Anniversary Celebration this fall. Details still need to be finalized, but we can tell you this much:

Date: Saturday, September 20, 2008

Where: New York Firehouse Museum, in the SoHo District of Manhattan
278 Spring St.
New York, NY 10013
<http://www.nycfiremuseum.org>

The non-profit museum has generously offered to allow DES Action celebration attendees to tour the fire museum's extensive exhibits without charge — and they are well worth seeing!

Please watch for more details in the DES Action *VOICE* Newsletter Summer Issue, which goes out in August. We'd be thrilled to have as many members as possible join us for this exciting event.

Looking Forward to 2008

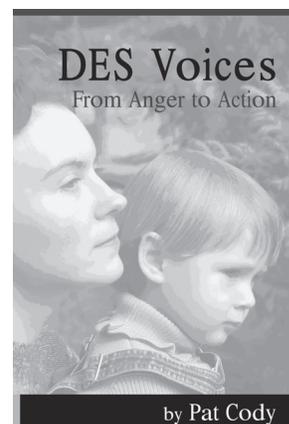
New Book About DES

It's been a long time since a new book has been published regarding the DES tragedy. DES Action Co-Founder Pat Cody, at the epicenter of the struggle for 30 years, has taken up the challenge and written our story — a saga of our DES experience.

The title tells it all. *DES Voices: From Anger to Action*, and each of us can understand it.

Cody, a DES Mother herself, includes many of the voices that are important to our struggle: DES Mothers, Fathers, Daughters, Sons, Attorneys, Researchers and Clinicians.

To order a copy of *DES Voices* send \$12.95 for each book (which includes shipping) to: DES Action, 158 South Stanwood Rd., Columbus, OH 43209. Don't forget your name, mailing address and contact information in case we have a question about your order.



Finances

DES Action remains financially stable and we are living within our means. The credit goes, in large part, to generous members like you, who have remained steadfastly loyal for many years.

As we look to the future, increasing costs, which are out of our control are of concern. Much of the budget goes to postage, which saw a price increase last year - and yet another one goes into effect this year. Similarly, the costs for printing are also creeping upward.

Those are areas we are watching carefully with the thought of someday moving some of our information distribution to email, where possible. Obviously, that's down the road and systems would have to be established so no one is left out of the information stream. We'll gather ideas from similar organizations that have already begun moving in that direction because all of us are now feeling the economic pinch.

DES Action is operating in the black, a statement many non-profits can only envy. We stay steadfastly focused on our mission of advocacy for those affected by the drug, diethylstilbestrol, and we have committed members who understand the need for what we do. DES Action has a long and solid history of getting things done for the DES community, while maintaining fiscal integrity — and we are proud of it. Thank you for your support of what we do.

2007 Revenue

Membership and Gifts	\$ 92,600
Miscellaneous Income	\$ 380
Total Revenue	\$ 92,980

2007 Expenses

Accounting & CPA	\$ 2,050
Board Meetings	\$ 6,270
Miscellaneous	\$ 780
Office Supplies	\$ 420
Printing and Mailing	\$ 16,170
Program Expense (CA Gov. conf.)	\$ 600
Salaries and Benefits	\$ 60,950
Utilities (phone, internet, computer expenses)	\$ 1,860
Other (one time expense - web redesign)	\$ 2,100
Total Expenses	\$ 91,200

DES Action Board of Directors

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We said a fond farewell to Nora Cody at the end of 2007, when her term on the Board of Directors ended. Nora has served DES Action for many years, as Executive Director and then on the Board. We still turn to her for advice and her input is sincerely appreciated. We thank Nora for her hard work on our behalf and wish her all the best.

DES Action Staff

Fran Howell
Executive Director

Kari Christianson
Program Director

Pat Cody
Voice Editor

DES Action USA
158 S. Stanwood Rd.
Columbus, OH 43209

800-337-9288
desaction@columbus.rr.com
www.desaction.org