

DES *Action*

ANNUAL REPORT 2006

When looking back at the year, one word comes to mind: **momentum.**

DES Action is moving ahead on many fronts.

There is positive news to report both operationally and financially, as well as from the research realm. We are pleased to share it with you.

Research Funding

Breast Cancer Risk

Advocacy

Financial Picture

Perhaps the biggest announcement of the year is that funding was approved for the **National Cancer Institute (NCI) DES Follow-up Study** to continue for another five years. This major DES research project follows the health of more than 20,000 DES Mothers, Daughters, Sons and now Granddaughters and is the largest scientific effort in the world regarding DES exposure. Behind the scenes DES Action has played an integral part in ensuring this large study keeps going.

Every five years participants fill out health surveys that are tabulated and compared with a similar unexposed control group. Much of what we are learning about DES health risks comes from this work. So it was cause for celebration when continued research funding was approved.

In 2006 a new batch of questionnaires was mailed to participants. The responses will keep scientists busy determining rates of all cancers, benign breast and gynecologic tumors, menopause experience, as well as other health issues possibly connected to DES exposure.

Research

By examining responses from previous survey mailings researcher Julie R. Palmer saw clearly that DES Daughters are nearly two times more likely than unexposed women to develop **breast cancer**, after age forty. Her work was published in the scientific journal, *Cancer Epidemiology Biomarkers and Prevention*, August 2006.

This is of potentially life-saving importance to DES Daughters, who should be sure to get annual mammograms and have their doctors do clinical breast exams when they go in for their yearly gynecological screenings. All women are also encouraged to do monthly breast-self exams.

Some DES Daughters had suspected they were at increased risk for breast cancer and were not surprised to find out they were right. Others were startled by the news:

"I feel caught in an ultimate irony...holding my breath until the Pap test came back negative, enduring the biopsies when it wasn't, but never worrying about my mammogram results. Now I know it could be the test that ultimately identifies a cancer for me. Of course I'll never skip my yearly mammogram now."

—Debbie

Another thing we learned from the *NCI DES Follow-up Study* is that **DES Sons are at slightly higher risk**

for infertility than unexposed men, but most can father children. The research, done by Kimberly M. Perez and published in *Fertility and Sterility*, December 2005, shows that DES Sons, in many cases, are able to overcome the hurdle. The number of DES Sons in the study who fathered pregnancies or live births is the same as for unexposed men.

What the researchers don't yet know is why DES Sons often experience infertility. The study does lead them to suspect that DES Sons may have increased difficulty with fathering children as they age. So scientists are looking forward to seeing the new questionnaires to revisit this issue with updated data.

The *NCI DES Follow-up Study* also gave researcher Elizabeth E. Hatch an opportunity to examine the **age of menopause** for DES Daughters. Her finding, published in the *American Journal of Epidemiology*, October 2006, shows that DES Daughters may experience slightly earlier menopause.

The study shows that for every two unexposed women who reach menopause at age 43, you could expect three DES Daughters of that age to experience natural menopause. It holds true that at all ages a greater number of DES Daughters achieved menopause, compared with unexposed women, up through age 54.

According to Hatch, "The average age at menopause was 52.2 years in unexposed women and 51.5 years in DES-exposed women." It may not seem all that important to individual DES Daughters, but for researchers the finding is significant because it reflects a statistical difference apparently caused by DES exposure alone. Hatch is very interested in reviewing the new survey results because more than half of the participants were still premenopausal when they filled out their forms in 2001.

Doctor Referrals

We saw a spike in requests for doctor referrals this year after the DES breast cancer study was released.

"Would you please send me a doctor referral list of doctors familiar with DES Daughters in central NJ? With the new revelations about breast cancer risks (I'm 51), I think it is time to make sure I'm seeing the right physician."

—Joan

What we can use are more names on our list! In some parts of the country, particularly in smaller cities and rural areas, we have no referrals at all. If you have a doctor you like and would recommend to another DES-exposed individual, please let us know.

Call our toll free hotline at (800) 337-9288, or email us at desaction@columbus.rr.com with your doctor's name and contact information.

In return, we'll send you a free button. Don't forget to give us your name and address so we can send it to you.

The more health care provider names on our referral list, the better it will be!



Advocacy

DES Action provided written testimony to a Food and Drug Administration (FDA) advisory committee considering the synthetic progestin drug "Gestiva" to prevent pre-term labor. Synthetic progestin has been in widespread use for this purpose but did not have regulatory approval.

DES Action opposes FDA approval of this drug, citing concerns for "the potential to create yet another pharmaceutical hormone tragedy with pregnant women and the children born to these women."

The letter, written by **DES Action Program Director Kari Christianson**, tells of animal studies indicating that neonatal exposure to progesterone results in vaginal and cervical epithelial lesions in mice, similar to what occurs with estrogen treatments, like DES.

Unfortunately, the advisory panel in a split vote recommended approval of Gestiva, while asking for further studies before and after final FDA approval.

We will continue to vociferously remind the FDA not to repeat hormonal mistakes of the past. But sadly, given the clout of Big Pharma, it is an uphill battle and it seems history is destined to repeat itself in this case.

At the National Institute of Environmental Health Sciences (NIEHS), recent changes have adversely affected DES research projects. As participants in the Public Interest Partners group, DES Action meets regularly with the NIEHS Director and will continue to make our concerns known.



As always, our newsletter carries accurate and timely research and information targeted for the DES community. During the year we've successfully experimented with ideas featuring so-called "news you can use."

In *Voice* 108 former Board member **Sally Keely** wrote an article detailing how to search for a DES-knowledgeable doctor. This is useful information for DES Daughters living in an area where our referral list has no names, or where insurance coverage mandates a health care provider change.

"Y'all do such a great job!! I just received the newsletter and have been thinking of changing gynecologists. It couldn't have come at a better time."
—Cathy

A current feature in the *Voice* is an **Ask the Expert** section with questions generated from our DES Action Daughters On-Line Support Group listserv. The feature is getting rave reviews and answers questions many of us have regarding a wide array of DES issues. We thank the experts who have fielded questions from us so far:

Candy Tedeschi, NP, (current DES Action Board Member) and nationally recognized DES expert, answered health care questions about cancer, menopause and the proper DES exam.

Patricia Stanford, Esquire, is a personal injury lawyer with an emphasis on pharmaceutical product liability cases. She has successfully handled DES claims and helped unravel the complicated world of DES lawsuits for us.

Julie Palmer, researcher, Boston University's Slone Epidemiology Center, authored the new breast cancer study and answered questions about it.

Jennifer Bailer, RN, is a DES Action member who works in breast cancer diagnostics. She graciously fielded questions about selecting a mammography clinic, and possible breast cancer symptoms to watch for.

Another popular column is, **Your Voice**, which gives members an opportunity to write about how they are living good lives in spite of, and with, DES exposure.

Sherry Weinman wrote the first one about letting go of infertility-angst and embracing the grandchildren brought into her family by her stepchildren.

Elizabeth Kate's *Your Voice* told her story of infertility, adoption and then the surprise of a biological daughter.

Now it's your turn. Your Voice feature editor Ann Giblin is currently collecting stories about how DES exposure was the spark that ignited your active participation in an activity or career "for the common good." It would be great to hear Your Voice telling that story. Please contact Ann at

ann@WinterlakeAssoc.com with your ideas. Provide just a sentence or two or — even better (!) — your 500-1,000 word article as soon as possible.

Finances

A combination of factors has contributed to a positive financial report that we are proud to share with you. Budget tightening is having an impact, while loyal members remain generous. Many of our members have been with us from our early days, going back to the late 1970s, which is something most other non-profits can only envy.

During this year the Centers for Disease Control and Prevention (CDC) did a survey to assess the success of its 2003 CDC DES Update education effort. Questionnaires were sent out to randomly selected DES Action members. To encourage participation we received \$25 for each returned survey — up to \$7,500. The response rate was so high it impressed the professional survey-takers, and we received a check for the maximum amount! Thanks to all who understood that by filling out the survey it would result in a financial boost for DES Action. It's terrific knowing so many of our members cared enough to do so.

2006 REVENUE	
Membership & Gifts	\$ 92,054
Miscellaneous Income	\$ 1,627
Total Operating Income	\$ 93,681
Other Income (survey)	\$ 7,500
Total Revenue	\$ 101,181
2006 EXPENSES	
Accounting	\$ 2,144
Board Meetings	\$ 6,015
Conferences & Mtgs	\$ 921
Dues & Subscriptions	\$ 110
Miscellaneous	\$ 136
Office Supplies	\$ 666
Payroll Taxes	\$ 2,217
Printing & Mailing	\$ 15,091
Staff Expenses	\$ 51,746
Utilities (phone, internet, computer)	\$ 2,346
Total Expenses	\$ 81,392

DES Action is well-grounded in the principles of accuracy and accountability. You've grown to trust our reports in the *Voice* newsletter, and you trust that we watch the bottom line with our spending habits. It's been that way from the start — when DES Action began in 1978.

We have an important anniversary coming up — **30 years!** We'll use the occasion to look back at what's been accomplished, before we look ahead toward what the future might bring. DES Action seems well positioned for continuing to make a real difference in people's lives, thanks primarily to generous support from our members.

Together, we've built **momentum**. DES research is continuing, the *Voice* newsletter is a must-read for the DES community, and DES Action's financial footing is stable. The result is a strong organization that gets things done. Thank you for being a part of it!

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