



ANNUAL REPORT 2010

How do you sum up a year that had been going rather well — until the very end?

We held our breath until word came through that, “yes,” DES research was approved for another five-year funding cycle. Published studies provided insights into health concerns for DES Daughters, Sons and Grandchildren. You read about them in the VOICE. And then we got the wrenching news that DES Action USA Co-founder Pat Cody had died at age 87 on September 30, 2010.

Pat — like Madonna and Cher — needs no last name. When we say “Pat,” you know we are talking about our Pat. Her impact resonates through the DES community. Pat was never the loudest voice in the room, but undoubtedly she was the wisest. Pat inspired us to work together around the DES issue in her firm belief that through teamwork mountains can be moved.

And move mountains she did. Do you think the federal government would have funded DES research and education without a strong push? Pat did not push alone. Her remarkable talent was empowering those best suited to fighting the good fight — and then turning them loose.



Words like “inspirational” and “legendary” come to mind when describing Pat. One DES Daughter called Pat “an Activist with a capital A who spoke when others wouldn’t and acted when others should have.”

In the end, Pat is most often remembered as “the DES Mother who is the Mother of DES Action!” She is sorely missed, but her impact will resonate forever.

RESEARCH

From the very beginning Pat understood the critical need for DES research. It was a priority then, as it remains today. As the funding cycle wound down in 2010, there was nervous anticipation for an announcement that was greeted with great joy when it finally came. The National Cancer Institute (NCI) approved another five-year cycle for DES studies, extending the program until 2016. Dr. Robert Hoover, Director of the NCI’s Epidemiology and Biostatistics Program and the DES Follow-up Study, says:

“Being able to follow the same group of people over many years is a major advantage of this type of research and enables us to try to understand the long-term consequences of exposure to DES.”

Planning began immediately to prepare for the 2011 distribution of the next health questionnaire going

out to participants. The survey is carefully and scientifically crafted so researchers can follow health experiences of DES Daughters, Sons, Mothers and now DES Grandchildren. Carefully matched to a control group, this scientific effort is one of the best methods for assessing the implications of DES exposure.

- New to the equation is a survey developed to follow the health of DES Grandchildren, with the first results published this year. A long list of birth defects was reported in DES Grandchildren, but none has been conclusively linked to DES exposure. Still, certain conditions appeared frequently enough to raise interest. The most common was hip dysplasia, which researchers hypothesize may be caused by the DES Daughter mothers having abnormally shaped and small reproductive tracts. What is not clear is why heart defects, including heart murmurs, atrial septal disease and ventricular septal defect, were also reported in DES Grandchildren.
- Another study published in 2010 stirred up interest. Using information from participants in the large Nurses’ Health Study II, researchers found that DES exposure may cause an increased risk for depression. The scientists concede that knowledge of DES exposure in itself could cause higher depression rates. However, the figures are compelling, with nearly 20% of DES Daughters reporting a history of depression compared with 16% in the unexposed group. As it turns out, one of the questions most frequently asked of DES Action is whether DES exposure increases the risk for depression.
- We’ll have to wait a few years for results of a major breast cancer study that started in 2010. The Sister Study by the National Institute of Environmental Health Studies has over 50,000 participants and is a 10-year long effort examining environmental and genetic factors relating to the disease. We are pleased that, like the Nurses’ Study, this one also is factoring DES exposure into the calculations.

COMMUNICATION

- Nearly 100 film insiders and DES Action members came together in Hollywood for a live staged reading of scenes from *WONDER DRUG*, a screenplay by DES Daughter screenwriter Caitlin

McCarthy. The afternoon was described as “wildly successful in spreading the word about DES!”

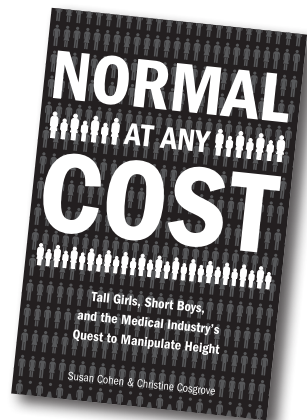
- Our most important member communication occurs via the DES Action VOICE newsletter, which has kept a focus on diethylstilbestrol.

Readers this year learned about both the Army of Women and Health of Women (HOW) research studies, which are recruiting and enrolling new participants. Those who sign up are encouraged to mention their DES exposure. Information was shared about DES Daughter breast cancer litigation, and we were pleased to spotlight the prestigious *Science In Society* award given by the National Association of Science Writers to DES Action USA Board member Chris Cosgrove. She co-authored *Normal At Any Cost*, describing how tall adolescent girls were prescribed huge doses of DES and other synthetic estrogens to stunt their growth.

Another VOICE issue this year untangled the complicated nuances of Pap guidelines issued by the American College of Obstetricians and Gynecologists (ACOG). While the updated recommendations call for less frequent Pap smears for most women, DES Daughters remain the exception and should continue with yearly Pap/pelvic exams. That was spelled out, but only in the fine print that many doctors will not read unless it is pointed out to them.

- Connecting DES Daughters with the ability to communicate via email on our DES Daughter Online Support Group listserv is another popular benefit of membership.

Thank you for your warm welcome and for approving me for the DES Daughters support group. I have always felt



alone in this struggle with DES. It had such a profound impact on my life, and yet I never reached out to another DES survivor. I think it is time I did, and I am so glad there is a group out there.

—Joy

DES Daughters, who are members, can join our group by sending a blank email to: DESactionDaughters-subscribe@yahoo.com

- Of course, we genuinely like hearing from all of our members through email: info@desaction.org and our toll free information phone line: 800-337-9288. Both the email address and phone number are also avenues for communication with individuals just learning about DES and wanting information about exposure.
- Many information seekers find us these days by googling “DES.” Our website (www.desaction.org) provides some of the most timely and accurate information available on the web.
- DES Action USA is part of the social networking revolution — connecting with members and the general public through our Facebook page. Clearly, it is working to connect individuals who need DES information.

I found this page via my cousin. I then went to the DES Action home page and looked at the Pap screening guidelines posted there. Thank You! My doctor had told me that DES Daughters were NOT an exception to the new guidelines. I think I'll print this and drop off a copy at her office.

—Beth

The stories of utmost concern these days are from DES Grandchildren, and many find us on Facebook. This young woman’s story reminds us that we cannot let our guard down with DES exposure.

I am writing in case my story may help others. I am what you call a ‘DES Granddaughter’ and I have DES side effects (not cancerous but on the reproductive side). My doctors have never heard of DES, so they don’t know how to look into it. I got married at 22 and miscarried my first pregnancy. Six months later I became pregnant with my son, who is a very healthy boy! When we tried for a 2nd child, I miscarried again, followed by an ectopic pregnancy. I just can’t help but believe there is a DES problem with me.

—Name withheld by request

FINANCIAL PICTURE

Connecticut-raised DES Action USA Co-Founder Pat Cody set our tone right from the start with a definite overlay of Yankee frugality in the way we operate. She was, after all, an economist and bookkeeper in her other life, so watching every penny came naturally to her. We carry on that tradition today.

Nonprofits are all chasing fewer dollars with money being tight all around. We have made changes to cut costs that do not impact our services. For example, our letterhead stationary is now printed in black-only, saving the expense of the extra red color. Information remains the same but is distributed at lower cost. Not a single complaint has come in.

What has not changed, though, is our flagship publication, the VOICE. It continues to be printed using both red and black ink, which seems well worth the expense for such a valuable newsletter and outreach tool.

This fiscal year resulted in a negative operating margin and that was disappointing. Although we did our best to achieve improvements in operational efficiency and expense control, we could not make up for the reduced donation volume. However, our years of frugality, as put in place by Pat, left us with carry-over cash from previous years that made it possible for us to pay our bills on time and operate effectively.

We are honored to have some of the most loyal and supportive members any group could hope to have. To you, we say, “thank you” and please know that your organization will continue just as you know it – the strongest voice for the DES community. We are advocating for continued DES research, while sharing what we learn to help those who need to know. The DES story is still unfolding in laboratories, doctor’s offices and courtrooms. You can count on us to keep you informed of the latest developments, as we have for more than three decades. DES Action USA has stuck to the core principles set forth by Pat, and that will not change!

2010 Revenue

Contributions & Membership Dues	\$ 71,788.52
Miscellaneous Income & Reimbursements	\$ 339.46
Total Income	\$ 72,127.98

2010 Expenses

Board Meetings	\$ 5,478.85
Computer Equipment	\$ 138.40
Conferences & Meetings	\$ 118.00
Dues & Subscriptions	\$ 190.00
Employee Compensation:	
Salaries: Pat, Kari, Fran	\$49,348.74
Employee Compensation: Medical	\$2,966.59
Employer Payroll Taxes	\$8,524.89
Total Staff Compensation	\$ 60,840.22
Fees and Permits	\$ 180.00
Insurance: Worker’s Comp & D&O	\$ 1,378.60
Office Supplies	\$ 108.76
Postage & Delivery	\$ 1,316.09
Printing	\$ 11,013.52
Professional Fees	\$ 1,827.51
Program Expense:	
CA Gov Conf & Script Reading	\$ 949.41
Utilities	\$ 1,734.87
Total Expenses	\$ 85,274.23

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The mission of DES Action USA is to identify, educate, support and advocate for DES-exposed individuals, as well as educate health care professionals.