



ANNUAL REPORT 2009

This was a year of communicating. Sharing the DES community's needs and concerns with government agencies, the U.S. Supreme Court, researchers, DES Action USA members and the general public. In some arenas the message was heard. Others need more reinforcement — and that is continuing.

DES Action USA remains the voice on many issues that directly affect our members. Perhaps the most important message we communicated this year is that DES research must continue into the drug's harmful effects now, and into future generations.

ADVOCACY

In testimony provided to the U.S. Office of Research on Women's Health (ORWH), we called for a renewed emphasis on DES research. Our message stressed the vitality of research results coming out of the National Cancer Institute DES Follow-up Study. Through the years we've learned of an increased risk of breast cancer for DES Daughters over age 40, along with a higher incidence of paraovarian cysts, uterine fibroids and endometriosis in DES Daughters. This is in addition to already recognized DES health concerns such as cancer, infertility, and reproductive tract structural anomalies. Now attention turns to the next generation affected by DES, the so-called DES Grandchildren. Recent preliminary studies have raised questions about overall fertility for this group, hence our call for research to examine this and other health issues.

Presiding over the public hearing was ORWH Director Dr. Vivian Pinn who was thrilled to reconnect with DES Action USA Co-Founder Pat Cody. After Cody gave her a copy of the book she'd written, *DES Voices: From Anger to Action*, Pinn sent a hand written acknowledgement and said,

" . . . the title is very fitting as that truly characterizes the essence of the movement. . . it reminded me of so much that took place in the early 90s here at NIH — and in the 60's when I was with Dr. Herbst at MGH (Mass General Hospital)."

We are proud that through the years DES Action USA has made and kept important contacts that turn out to be helpful when we want to ensure that our message is heard. We have developed a reputation as a respected and accurate resource for DES information and advocacy, which we work hard to maintain.

PARTNERS

Partnering with like-minded organizations and individuals serves us well, too. Groups such as Breast Cancer Action, the National Women's Health Network and the Center for Justice and Democracy share many of our concerns regarding pharmaceutical industry influence on doctors, as well as limiting endocrine disruptors in the environment. By working together we increase the odds of success.

- We have joined with the National Coalition for Appropriate Prescribing in support of the Physicians Payment Sunshine Act. It asks Congress to limit marketing of drugs by curtailing the promotional gifts and payments drug makers hand out to doctors. This resonates with us because DES was heavily marketed to doctors even though research in the 1950s showed it did not work to prevent miscarriage. Yet DES was widely prescribed after being massively promoted by the pharmaceutical industry as the drug of choice to give pregnant women. Obviously, the results were tragic.
- Many of our members have joined with us in an effort to remove from the nation's dairy supply a synthetic estrogen linked to breast cancer. DES Action USA is partnering with Breast Cancer Action in a petition drive telling Eli Lilly to stop making rBGH, which is given to cows so they produce more milk. Conveniently, Eli Lilly also manufactures breast cancer treatment drugs. It really is as outrageous as it sounds. Eli Lilly is milking cancer. Go to www.desaction.org under the What's New section for a link to the petition.
- Another way DES Action USA keeps lines of communication open is through our participation in The Collaborative on Health and the Environment (CHE). Regularly scheduled conference calls bring together advocacy organizations, like ours, with scientists who share and discuss their research. As the



The logo consists of a stylized cow's head silhouette on the left, with the word "milking" written in a cursive, handwritten-style font across the top of the head. Below "milking", the word "CANCER" is written in a bold, blocky, sans-serif font.

world's first recognized endocrine disruptor, there is interest in how DES is affecting those directly exposed and the generations that follow.

GOOD NEWS!

- March 4, 2009 was a day for celebrating because the nation's highest court upheld the right of individuals to sue drug companies and recover damages for their injuries. Our concerns were communicated clearly in an Amicus Brief written by Attorney Aaron Levine. It spelled out why DES-exposed individuals should not lose the right to sue the manufacturers of DES. What we told the Supreme Court Justices was that individuals should be allowed to file lawsuits even if they concern FDA-approved drugs, like DES. In the 6-3 ruling the Court rejected drug company arguments, thereby allowing DES cases, and other product liability lawsuits, to continue being filed.
- We were pleased this year with the appointment of Linda Birnbaum, Ph.D. as the new director of the National Institute of Environmental Health Sciences (NIEHS). One of her areas of interest is learning how fetal exposures (like DES) become the basis for adult disease. She has communicated her understanding of the importance of DES for research and we stay in touch to reinforce her interest in our issues.
- Another appointment of note this year put long-time DES Action USA friend Dr. Sidney Wolfe on the FDA Drug Safety and Risk Management Advisory Committee. Wolfe, director of the Public Citizen Health Research Group, was an early DES whistle-blower and is known as a drug safety crusader. In Pat Cody's words, "At last — a real watchdog at the FDA!"



Mothers, Daughters and Sons who were spurred into action to discuss DES with their children. The brochure we developed specifically for DES Grandchildren helped by explaining to them what it means to be DES exposed, and why they need to pay attention to DES as part of their health histories. To request a copy email: info@desaction.org or call 1-800-337-9288.



- The DES Daughter On Line Support Group listserv is steadily growing. Participants value this benefit of membership because it provides an opportunity to communicate with DES Daughters around the country. Here's how one member describes it:

"The on line support group keeps me connected to people who know what I am going through. I can ask questions and find out what other DES Daughters did in my situation, allowing me to benefit from their experiences."
— Sharon

DES Daughters, who are members, can sign up by sending a blank email to: DESactionDaughters-subscribe@yahoogroups.com

- We keep a focus on diethylstilbestrol in the DES Action VOICE newsletter. Through the year we shared articles on how scientists are unlocking the mysteries of why DES causes harm, we confirmed that DES was prescribed after 1971, we reported on new understandings as to how dose and timing of exposure matter to DES Sons, and we debunked the misconception that DES was banned for human use — because it never was!
- DES Action USA now has a Facebook page. Come visit — and friend us! And, while surfing the Internet, stop by our web site at www.desaction.org where accurate DES information is available whenever you need it.



MEMBER COMMUNICATION

- Our *Information is Power — Tell Your Children About DES* effort this year proved highly successful. We heard from numerous DES

FINANCIAL PICTURE

DES Action USA relies solely on members for our operating expenses. When grants and government funding dried up this year, it hurt many organizations but had no impact on us. Still, times are difficult for all and we are feeling the effect. Most of our members have stayed with us because they understand the value of the DES information and advocacy we provide. Some can't give as much as in the past though, and it shows in our financials for the year.

This is not meant to frighten or depress but rather to lay out the challenges we face in fulfilling our mission of serving the DES community during these tough economic times.

We were lucky to start this fiscal year with cash that was carried over from previous years. Even though expenses in 2009 were higher than income for the year, our frugality coupled with the carried forward funding gave us the cash reserves needed to pay all the bills.

DES Action USA has always been, and will continue to be, fiscally responsible. That mind-set serves us well now as we navigate the current national economic downturn. We have loyal members who understand the value of supporting our work, and we thank you! Have no doubt — we are a gutsy group that can get through this time. We will be around for as long as those of us in the DES community need answers and a strong advocate for our cause. You can count on that!

DES Action USA will be around for as long as we are needed because our members find value in supporting the work we do. Thank you!

2009 Revenue

Book & T-Shirt Sales	\$ 710
Contributions & Membership Dues	\$ 74,700
Reimbursements	\$ 300
Total Income	\$ 75,710

2009 Expenses

Anniversary Costs	\$ 1,920
Board Meetings	\$ 4,260
Conferences & Meetings	\$ 650
DES Action Book Shipping	\$ 175
Fees & Permits	\$ 660
Miscellaneous	\$ 140
Office Supplies	\$ 400
Payroll & CPA Services	\$ 3,010
Payroll & Employer Taxes	\$ 14,970
Printing & Postage	\$ 13,800
Prog Expense – CA Gov Conf	\$ 475
Salaries, Medical Benefits	\$ 47,660
Utilities (phone, internet, p.o. box, etc.)	\$ 2,090
Worker's Comp	\$ 1,275
Total Expenses	\$ 91,485

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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.