DES Action

ANNUAL REPORT 2008

Celebrating 30 Years of Action

Not many small consumer groups that percolated up from the grassroots activist years of the late 1970s still flourish today. We are an exception and going strong!

The year was spent honoring our 30th anniversary, while continuing the all-important work of advocating for the DES community.

We reached our important 30-year milestone with pride for the accomplishment and with determination to meet the challenges ahead.

Communication is one of the most important tasks done by DES Action. We stay in touch with researchers, so they know the health issues being experienced in the DES community. Information from DES Action members helps to guide future areas of study. On the flip side, we act as a conduit for distributing the DES research results that are so vital for us, as individuals to make decisions about our own health care.

DES Action VOICE

One avenue for sharing such information is the DES Action VOICE newsletter. During this special year, we took time out to honor those who've helped us along the way. We planned to recognize 30 but couldn't whittle down the list and ended up with 35 invaluable individuals. Their talent, energy and enthusiasm kept us on the right track for three decades, and so our thumbnail sketches — while not able to explain their full range of contributions — was our way of recognizing their help.

Another important communication tool is the DES Action DES Daughters On Line Support Group listserv. Participation has grown this year, while our discussions have remained completely focused on DES issues. To join just send a blank email to: DESactionDaughters-subscribe@yahoogroups.com.

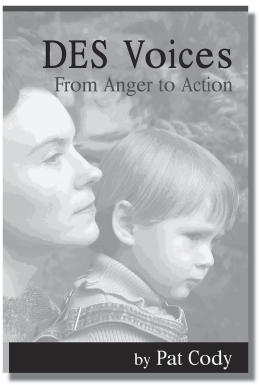
Members of the support group are thrilled to be a part of it. Here is how one put it:
"I love how the discussions have become so detailed and sophisticated. I especially love the support we provide one another since there is no one who can fully understand and appreciate the specific needs of DES Daughters more than we can."

The more participants we have the better the conversations. If you are a DES Daughter, we urge you to consider joining this excellent DES Action USA benefit of membership.

New Book

We have been pleasantly surprised by all the interest shown DES Action Co-Founder Pat Cody's book, ***DES Voices: From Anger to Action***. It is a huge success and the first printing sold out in just two months!

Cody describes how grass-roots activism took hold in pre-Internet America. Looking back on it now, we can only wonder how this small band of primarily DES Mothers used telephones, mimeograph machines and hastily called meetings around dining room tables to mobilize in far-flung cities. Truly an amazing story of determination and accomplishment, and it is our story.



To order your copy send $12.95 for each book (which includes shipping) to: DES Action USA, 187 Via Catalunha, Jupiter, FL 33458. Don't forget your name, mailing address and contact information in case we have a question about your order.

Office Updates

Something exciting happened in the office this year, when we **upgraded our computer and software**. The equipment, circa the late 1990s, had come to the end of its useful life. After years of working around glitches in the old system, using the new technology was awkward at first. However, it didn't take long to see the advantages. Now the office runs more smoothly and efficiently than ever.

This is the year we **moved** from Columbus, OH to Jupiter, FL, where the husband of Executive Director Fran Howell landed a job and the office traveled with her. Aside from a new address, nothing else changed except the view from the office window — which now includes palm trees!

Research

Two **research** studies this year increased our understanding of DES exposure. The first, published in the Journal of Lower Genital Tract Disease, Vol. 12, No. 2 by Elizabeth Camp, et al, found that most DES Daughters have annual Pap/pelvic screenings — but a surprisingly large number do not. Researcher Camp found that despite recommendations for annual exams, 29% of the responding DES Daughters in the National Cancer Institute (NCI) DES Follow-up Study survey had not had a Pap/pelvic screening in the past five years. She speculates that access to health care and insurance status may be to blame.

The second study showed no overall increased cancer risk for the children of DES Daughters — however, it did hint at the possibility that ovarian cancer in DES Granddaughters could be of concern and needs further study. Published in the journal, Epidemiology, Vol. 19, No. 2, Linda Titus-Ernstoff, et al, analyzed results from the NCI DES Follow-up Study and gave us the reassuring news about no overall increased cancers in DES Grandchildren. But she warned that the incidence of ovarian cancers in this group must be watched in coming years. DES Action is staying on top of this research and will share the latest information, as soon as it is available.

Advocacy

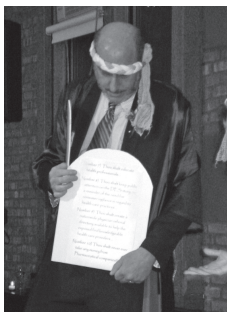
DES Action is trying something new in the field of advocacy. Thanks to DES Action Board of Directors Vice President Karen Fernandes, we are now represented on the Consumer Council of the National Quality Forum (NQF). This Washington based organization's mission is to improve the quality of health care. Fernandes is introducing the health screening needs of DES Daughters, which include annual Pap/pelvic exams and mammograms over age 40. She is also working to have possible screening requirements for DES Mothers, DES Sons and DES Grandchildren acknowledged, should they be needed in the future.

Once drafted, the official NQF guidelines will be published and used as a measurement tool by the government, insurance providers and physicians. This is a new approach to getting our message heard and potentially will have a major impact on the way healthcare is delivered to those of us who were exposed to DES.

Celebrating 30 Years of Action!

During this special year we took time to **honor our past and look ahead to the future**. In April there was a small reception to recognize those who helped give life to the mission of DES Action USA. Hosted by **Nancy Hersh, Esq.,** at her San Francisco home, we brought together the Founding Mothers of our organization, along with DES researchers and Board Members past and present. They are the passionate, dedicated and brilliant individuals who set us on our successful path. Having them come together was energizing and exciting, as we heard stories and shared laughs about the "olden" days.

The larger celebratory event was open to all members and held in September in New York City. What a gathering! We had fantastic music, awesome food and plenty of hugs. Thanks to our sponsors: **Aaron Levine, Esq., Michael London, Esq., Sybil Shainwald, Esq.,** and **Patricia Martin Stanford, Esq.,** this fundraising party was a huge success — bringing in more than $8,500 in profit! We were able to hold our celebration at the New York City Fire Museum thanks to **Fred Eichler** and **Dorothy Marks**.



Perhaps most memorable was an entertaining examination of DES Action history as presented by Brain Brew Entertainment, whose owner and producer is DES Action Board of Directors President Patti Negri, who enlisted Board Member Michael Freilick in the skit, as Moses.

We were thrilled that several DES families came to the event, reminding us that DES affects us all: Mothers, Fathers, Daughters, Sons, Husbands, Wives and Grandchildren. This is a family issue and we are committed to all generations — especially now as DES Grandchildren mature. Science tells us we must pay attention to their needs, too.

We heard from many members this year about our anniversary.

DES Daughter Betty Fagen said:
"Thank you for 30 years of dedicated work, knowledge, compassion, support, and most importantly, "The DES Sisterhood!"

DES Mother Martha Cotiaux told us:
You are all very dear to my heart. A light in the tunnel back in the 70s when I felt so alone!

DES Daughter Lisa Greene summed it up perfectly:
"I have, over the years, turned to DES Action for information and support. I thank you for the community you have created, the awareness DES Action has raised and the action DES Action has demanded."

We recognize the importance of our strong and loyal membership base and thank all of you — those who were able to attend the anniversary gathering, and those who were there in spirit.

Our major challenge is financial, as we head into a rocky national economic environment. It began to show this year, when our income slipped below our expenses.

DES Action has never accepted drug company funding, and we currently have no corporate grants. We have never depended on grants, which is now a relief because those revenue sources are quickly drying up.

We want to express our sincerest gratitude to our loyal members who continue to support our work.

You have been generous through the years. This is not an easy economic time to be a non-profit, but we are frugal and fiscally responsible. Those values have served us well for three decades and nothing changes now. We are carefully monitoring our budget and doing what we can to lower expenses.

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!

2008 Revenue

Anniversary Gifts & Sponsor	$ 27,177
Book Sales	$ 3,721
Membership & Contributions	$ 88,991
Reimbursements	$ 710
T-Shirt Sales	$ 135
Total Revenue	$ 120,734

2008 Expenses

Anniversary	$ 16,896
Board Meetings	$ 8,962
Book Printing & Shipping	$ 9,299
Computer/Software/Repair	$ 3,387
Fees & Permits	$ 445
Conf & Meetings ($710 reimbursed)	$ 752
Miscellaneous	$ 30
Moving Expenses	$ 1,100
Office Supplies	$ 711
Payroll & CPA Services	$ 3,852
Payroll Taxes	$ 14,969
Printing & Postage	$ 15,411
Prog Expense – CA Gov Conf	$ 375
Salaries, Benefits	$ 45,293
Utilities	$ 2,116
Worker's Comp	$ 387
Total Expenses	$ 123,985

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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.