

DES *Action*

A N N U A L R E P O R T 2 0 0 5

.....

A Year of Transition

.....

A Proud New Look

.....

Important Research

.....

Financial Report

.....

The real test of an organization comes during transitions, when individuals who've been successfully running things for years pull back, and a new administration gets to work. Last year DES Action passed the test with flying colors!

So much here has changed. Our new executive director, Fran Howell, lives in Columbus, Ohio, so the office moved there. We have a new look, with redesigned letterhead and a bright new feel to the Voice. We've even learned to operate as a tri-state operation, with Program Director Kari Christianson in Minneapolis and Voice Editor Pat Cody in Oakland. We've developed new communication skills, primarily via email.



What hasn't changed is our adherence to principles that have kept DES Action vital for 28 years:

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

In fact, it's so important we now print our mission statement on page two of every Voice newsletter.

DES
Action VOICE

Have you taken a close look at the Voice lately? The new design was rolled out last spring to rave reviews.

"Yesterday I received the Summer 2005 edition of DES Action Voice...Keep up the good work!

—Sincerely, Sharon

But even as the look changed, it's contact remains intact. The Voice is full of valuable information you can't get anywhere else.

A new and exciting feature is the *Your Voice* column, where members share personal stories showing how they are living good lives in spite of, and with, DES exposure. Board Member **Ann Giblin** is collecting your stories. Contact her at: Ann@WinterlakeAssoc.com and put DES Your Voice in the subject line.

The summer Voice featured a clip-out fact sheet on how the annual gynecological exam should be done for DES Daughters. It is now one of our most requested documents.

"Do you by any chance have any of those Pap exam sheets around and could you please mail me one? My yearly is coming up soon (yippee)."

—Joy

If you'd like a copy just email the office at desaction@columbus.rr.com, or send a self addressed stamped envelope to DES Action, 158 South Stanwood Rd., Columbus, OH 43209.

Research

We learned several interesting new things about DES exposure this year. For example, DES Daughters are at increased risk for **endometriosis**. Stacy A. Missmer, et al, published their findings in *Fertility and Sterility*, Vol. 82, No 6, December 2004.

The researchers examined information from the Nurses' Health Study II, which followed more than 84,000 females for a decade. They found the rate of endometriosis was 80% greater among women exposed to DES in utero compared with non-exposed women. Further analysis showed that the trimester of initial exposure did not affect the rate of endometriosis, but any DES exposure of five or more weeks nearly tripled the rate, compared with DES Daughters exposed for less than five weeks.

We also learned this year that **uterine fibroids** should be added to the list of long-term health problems DES Daughters may experience. Donna Day Baird and Retha Newbold's study was published in *Reproductive Toxicology* 20 (2005).

Fibroids, or non-cancerous tumors, sometimes cause pain, bleeding, infertility and pregnancy complications. Baird and Newbold, who work at the National Institute of Environmental Health Sciences, had previously found a link between DES exposure and uterine fibroids in mice. To see if it held true for humans they studied 858 women and found a higher proportion of DES Daughters developed fibroids than their non-exposed counterparts. The study also showed that DES Daughters developed larger fibroids as well. What isn't yet clear is whether tumors in DES Daughters start growing sooner, or grow faster, or both.

More research results this year show that DES exposure is positively associated with **paraovarian cysts**. In an article published in *Obstetrics & Gynecology* (Green Journal) by Lauren A. Wise, et al, the researchers found that "developing reproductive organs are a potential in utero target for the long-term toxic effects of DES."

Parovarian cysts are noncancerous fluid-filled sacs adjacent to, but not part of, the ovary. Treatment is generally surgery, depending on symptoms of discomfort and pain. Some women with cysts have no problems and need no treatment.

New in 2005

We tried something new in the spring, by sponsoring a talk by women's health journalist **Barbara Seaman**. It was part of Prevention Is the Cure week on Long Island. Seaman, author of *The Greatest Experiment- Ever Performed on Women: Exploding the Estrogen Myth* discussed the history of DES to an appreciative audience. Thanks to this event, several lapsed members re-joined. An excellent side-benefit of the talk!

Something else new this year was the creation of On-Line Support Groups, one for DES Daughters and the other for DES Sons. There is something comforting about communicating with others who don't need to be told what DES is. We learn from each other by sharing experiences and suggestions for dealing with health issues relating to exposure.

We thank members **Sally Keely**, **Molly Spira** and Board Member **Michael Freilick** for setting up the listservs and helping moderate them. If you'd like to participate in our email discussions simply send a blank email to:

DESactionDaughters-subscribe@yahoogroups.com

or

DESactionSons-subscribe@yahoogroups.com

One of our members, **Caitlin McCarthy**, had a terrific idea. She suggested selling T-shirts as a fundraiser and they've really caught on.



I absolutely love the T-shirt. It fits great and looks fantastic on me. I wear it proudly.

— Pat

I got one for my Mom and while she was on a treadmill at the gym she noticed a man was staring at her. When she looked at his shirt it was for (drum roll please!) Bristol-Meyers Squibb! She said she couldn't help smiling.

— Jill

An exciting thing happened this year when DES Action was recognized as a major player in the women's health movement. The highly regarded National Women's Health Network (NWHN) selected DES Action Co-Founder **Pat Cody**, long-time former Executive Director, and current Board Member **Nora Cody** and the entire DES Action organization for recognition.

As part of the NWHN's 30th anniversary celebration, 30 women's health activists and organizations were singled out for their work. DES Action is extremely proud to be counted among this prestigious group as we continue our advocacy and support initiatives.

Donations and membership contributions continued a downward trend started several years ago. We suspect they were exacerbated this fiscal year because our move wrecked havoc on our mailing schedule. Unfortunately, renewal notices went out within weeks of special appeal letters as we struggled to get the new office up and running. Now that we are well into our second year following the move, things are falling into place. We are getting back into a rhythm and predictable schedule. The new, oversized wall calendar in the office certainly helps!

On the plus side, the move gave us a chance to renegotiate contracts, such as telephone and mailing service, to save money. That will be reflected in next year's financial picture. Our Fall Board of Directors Meeting was in Oakland, California, where Co-Founder and Voice Editor Pat Cody hosted the group for dinner at her home. Ahh, the roasted chicken, potato casserole and homemade applesauce! It was reminiscent of our early days when organizing took place around the kitchen table. DES Action is a strong and proud organization — made so by our loyal members. We thank you for your support!

Financial Picture

2005 REVENUE

Membership & Gifts	\$ 86,564.50
Interest	\$ 2,658.31
Publication Sales	\$ 552.75
Miscellaneous	\$ 240.00
Total Revenue	\$ 90,015.56

2005 EXPENSES

Staff Expenses	\$ 48,466.72
Taxes	\$ 2,266.60
Benefits	\$ 2,504.83
Accounting	\$ 1,855.00
Printing	\$ 10,970.05
Mailing	\$ 13,236.65
Utilities (phone, computer, etc.)	\$ 3,083.79
Board Meetings	\$ 6,640.52
3 Months Rent	\$ 3,006.00
Accounting	\$ 1,855.00
Miscellaneous	\$ 812.27
Total Operating Expenses	\$ 94,653.72
Transition/Move	\$ 2,504.70
Total Fiscal Year Expenses	\$ 97,158.42

DES Action Board of Directors

Patti Negri
President

Michael Freilick
Vice President

Nora Cody
Secretary

Stephanie Kanarek
Treasurer

Karen Fernandes

Ann Giblin

Kim Mazeris

Cheryl Roth

Candy Tedeschi

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