

New Staff and Office

2005 brings changes for DES Action. Nora Cody has left us for a position with the Oakland Unified School District working on children's health. We have a new Executive Director, Fran Howell, and Program Director Kari Christianson. The office is moving to Fran's city of Columbus, Ohio. desaction@columbus.rr.com
Pat Cody continues as editor of

the VOICE and as research liaison from her home office in Berkeley, California.

We have new services for members: a DES daughters listserv and a DES sons listserv. We continue the services already familiar to readers: physician and legal referrals, and advocacy for research, especially on the third generation. ■

A New Chapter

By Nora Cody

FIFTEEN years ago I returned from the East Coast to my hometown of Oakland, California with my husband-to-be and the desire to find meaningful work. I was fortunate beyond my hopes when I was hired as DES Action's executive director. Nervous but excited, I began a job and an incredible journey at the same time.

So much has happened since 1990. We've passed two bills in the United States Congress, renewing and expanding DES research funding and establishing the first-ever National DES Education

When I think about what I will miss most, I hear the voices of the individual men and women of DES Action.

Program at the Centers for Disease Control and Prevention. The Internet became a vital part of our lives and changed communication forever. We held national conferences and told our stories before the National Cancer Institute and many others. DES Action groups have grown and developed in Canada, Australia, The Netherlands, England, and France. All the while answering your phone calls, emails, and letters; listening and learning.

When I think about what I will miss most, I hear the voices of the individual men and women of DES Action. I have had the privilege of working with some truly fine and dedicated people. It has been an honor to work

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Fran Howell

FRAN HOWELL spent most of her youth in northern New Jersey, with a transistor radio pressed against her ear. That passion turned into a career in broadcast journalism, which took her to jobs at radio stations in cities all around the country. She has lived in such cities as Portland, ME; Trenton, NJ; Boise, ID; Seattle and Houston. After marrying fellow journalist Kevin, in Texas, they continued their wandering ways by living together in Huntsville, AL; Scranton, PA; Minneapolis, and finally, Columbus, OH.

While in Houston, Fran made the switch from radio news to media relations. She began as a Specialist with the University of Houston Office of Media Relation, but after six years of promotions was named director of the department.

It was in Houston that Fran started paying attention to her DES exposure. When it came time to start her family, it didn't happen the way it did for her friends. Numerous infertility treatments later – there was still nothing to show for it. Eventually, Fran and Kevin became adoptive parents to their wonderful daughter, Shelby, who is now



DES Action's new Executive Director, Fran Howell.

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Join the DES Action Daughters or Sons Listserv

To join the **DES Action Daughters** listserv simply send a blank email to: DESactionDaughters-subscribe@yahoogroups.com

To join the **DES Action Sons** listserv simply send a blank email to: DESactionSons-subscribe@yahoogroups.com
For news about this exciting new benefit, see story page 7.



Yes—I want to get answers about DES. Enclosed is my membership.

All members receive **The DES Action Voice** quarterly. Those at the \$100 level and above receive an annual report on DES Action's work and progress. All contributions are tax deductible.

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☐ DES Mother of a: ☐ Daughter ☐ Son

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 Address _____
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DES Action Affiliates and State Contacts

DES Action Affiliates

Each affiliate was created and nurtured by volunteers. Write to them if you want information or would like to volunteer.

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State contacts participate in national projects organized by DES Action. Contact the national office if you would like to find out about our national projects.

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Kari Christianson

KARI CHRISTIANSON, DES Action's new Program Director, has been a volunteer with DES Action for 25 years, starting as one of the founding members of DES Action Minnesota in 1980. She served as President of DES Action USA from 1984-1989 and again from 1998-2001. Kari is a DES daughter and is a participant of the Mayo Clinic cohort of the DESAD Project, now the NCI DES Follow-Up Study. Kari was a consultant to the University of Wisconsin-Madison DES education pilot project for the NCI and served on the CDC's DES Update Working Group. For the past two years Kari has

been the DES Action representative to the Steering Committee of the NCI DES Follow-Up Study

In addition to her activities with DES Action Kari is an active volunteer with her congregation and has served in a number of elected offices with the Church. Currently she is serving her second four year term as Vice President of the Minneapolis Area Synod of the Evangelical Lutheran Church in America. Work experience includes retail/wholesale sales of Scandinavian music, children's books and literature and alumni/church relations development for a liberal arts Lutheran college.



Kari Christianson

Kari and Milo, her husband of 33 years, happily dote on their three nieces and one nephew.

"Working with the dedicated staff and volunteers of DES Action always has been a source of inspiration and a privilege. As the new Program Director, I fully appreciate the opportunity of working with our members as we continue together to tackle the challenge of keeping the issue of DES exposure in the minds and actions of legislators, researchers, medical professionals, and the public."

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alongside my mother, Pat Cody, who has led this organization with integrity and vision for many years. I also count among my personal heroes the two women who are taking the helm – your

new staff
Fran
Howell and
Kari
Christianson.
And there
are many
others who
continue to
serve this



Nora Cody

organization both on and off the Board of Directors: DES Sons Network director Mike Freilick, past-president Molly Berigan Spira, DES Third Generation Network Elizabeth Wandelmaier, former Board member Libby Saks—one of the early activists among DES mothers — and many more.

There are also many women and men whose names I will never know but whose stories and voices have touched my heart over the years. I can't tell you how many times I have heard a DES daughter, struggling to come to terms with serious health problems no one should have to bear, compare herself to another woman with seemingly worse problems and count herself "lucky." The resiliency and grace that characterize our community continues to inspire me. My own problems are always put into perspective.

While I have made the difficult decision to leave my paid position as your Executive Director, I am not leaving DES Action. I will continue to serve, this time as a volunteer on the Board of Directors. I look forward to working to contribute to our future gains and to helping the new staff in any way I can.

For those who are curious, I have begun work in a new job with the Oakland Unified School District. I will be coordinating several different health-related programs for this large, urban district, and focusing on my own interest in children's health.

FRAN HOWELL from page 1
13-years old.

Fran joined the DES Action Board of Directors during her time in Minneapolis. When the opportunity arose to assist with media relations for the organization during the CDC's DES Update effort, Fran jumped at the chance. She worked with newspaper, TV and magazine reporters to successfully place dozens of stories about DES. Her hope is to continue doing that in the future, because the need for educating the public and health care providers remains a priority.

Letter to the Editor

Dear Editor:

I have some important information that I would like to share with DES daughters. I am a nurse who has suffered unbearable pudendal nerve entrapment pain and neuropathic pain and loss of function due to compression and denervation (neuronal cell injury/death).

Because of the extensive congenital anomalies that were not apparent on MRI, and caused unspeakable pain along the sacral 2,3,4 (pudendal nerve distribution), I am wondering if other DES daughters are suffering from this type of neurogenic pelvic pain and are being misdiagnosed.

The signs and symptoms of PNE often include an increase in pain with sitting (inability to tolerate), radiating pain in buttocks, anorectal, perineal, urogenital, posterior thighs and groin or panty line with possible dysfunction to the organs that the pudendal nerve innervates: bowel, bladder and sexual organs, pelvic floor muscles (pubococcygeal sling).

The neuropathic pain can manifest and change character, but may include burning, electric shooting shock sensations, ice pick or needle piercing sensations, unpleasant tingling, sword penetrating, or sensation of objects in rectum or torsion/tugging/pulling.

The pain and dysfunction are humiliating and debilitating. When women report this to MDs who are unfamiliar with PNE, the MDs do the

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"blame and defame the patient by labeling them insane" response, instead of admitting that they are stumped and have never encountered a pain syndrome like this before.

I have suffered pelvic pain and dysfunction for 5-1/2 years and am now recovering from my surgical release and am slowly improving, although the neuropathic pain may persist for up to two years post-op.

I just had neurosurgical pudendal nerve release in Houston, Texas by the best PNE team in the country. The surgeon was Lee Ansell, MD and the PNE team leader Ken Renney, MD is also a PNE sufferer when he was hit by a car while cycling.

The neurosurgeon found extensive bilateral congenital anomalies of the nerves, ligaments and bone within the pelvis, mechanically entrapping the pudendal nerves. He had never seen such anomalous nerve branching and abnormal compartments of the nerve branches. I had four rather than two fascial pudendal or alcock's canals through the side walls of the vagina. He unroofed or did a fasciotomy of each, releasing the nerves from a carpal tunnel type entrap-

ment. I also had abnormal conjoined or fused sacrotuberous and sacrospinous ligaments, through which the nerves were abnormally routed and tethered.

I think that some of the anomalies that were only visible to the neurosurgeon as he traced the abnormal nerve branching occurred in the mullerian tract which may mean that my recently discovered PNE congenital anomalies could possibly be DES related or linked. This could be quite valuable information if it is indeed a real teratogenic link.

PNE is also known as the cyclist syndrome from over-cycling (Tour de France). It can also occur as a result of instrumentation damage from compressive pressure on the pudendal nerves after a vaginal hysterectomy, forceps deliveries, prolonged pushing or childbirth trauma, chronic constipation, being injured in a seated position (falls, cycling, prolonged sitting, motor vehicle accidents, etc.). I sustained traumatic damage after a prolonged vaginal ultrasound where the sonographer dragged the transducer probe across the pudendal canals in the side walls of the vagina, which

Some of the anomalies ...occurred in the mullerian tract which may mean that my PNE congenital anomalies could possibly be DES related or linked.

Book Notes

by Pat Cody

Coming to Term: Uncovering the Truth about Miscarriage, by Jon Cohen. Houghton Mifflin, 2005, \$24.00

The author's personal experience—his wife after a successful pregnancy had four miscarriages in a row—led him to use his research and writing skills “to write the book that I wish had existed when miscarriage had us in its throes.” He discovered that a woman's biology causes 90% of the miscarriages because of either an extra or a missing chromosome. He also has some encouraging news: when women who had had three or more miscarriages one after the other become pregnant again, nearly 70% of the time they do carry to term.

He and his wife hadn't known that—and he points to the lack of research (only one Recurrent Miscarriage Clinic in the United States) as the reason for so many unproven treatments. He refers to DES, and then adds that “today, a Wild West mentality still exists in the miscarriage field, an oft-ignored branch of medicine.” Later in this book, Cohen states that “miscarriage is one of those oddities in medicine: a common condition that has few true specialists...no one offers a degree in miscarriology. There is no *Journal of Miscarriage*, no Society of Miscarriage Medicine that holds an annual meeting, and no formal assessment of the miscarriage care that does exist.” Two pages later he addresses the reasons: physician Joseph Hill tells him, “Ob-gyn is largely procedure-based. The differential of what can be made

for procedures versus office consultations is two to three times...This is very labor-intensive and reimbursement is largely lacking.”

The lack of research, and the “Wild West” mentality, certainly is shown in DES treatment. Cohen has an entire chapter (“Really?”) on this, profiling the experience of our new executive director Fran Howell and her mother Trudy Merzbach, and concludes that “Deciding to do nothing, in an informed way, often constitutes the most prudent way to do something...the DES debacle warns that, as much as possible, any woman struggling to have a baby would do well to evaluate first whether they have an underlying biological problem and then, if offered a treatment option that supposedly has a proven record as safe and effective, to ask, from every imaginable angle, Really?”

In the following chapter “Anatomically Incorrect” the author notes the caution of Professor James Harger from the University of Pittsburgh who counsels that “off-label use of drugs and unproven surgical interventions, especially in patients desperate to have a baby, require a much more restrained approach than now typically occurs.”

Earlier chapters describe other reasons for miscarriage, and some treatments in use. The book ends with a chapter on “Expert Care” and, finally, one on “Miracle Babies.” It turns out that tender loving care for women with pregnancy loss may really help them carry to term

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provoked a fire storm of swelling, excruciating neuropathic pain and functional losses.

I believe in my heart that many women suffering from urogenital and/or anorectal or ‘pelvic pain’ are being misdiagnosed like I was for 5-1/2 years. Most appalling is the fact that I found my own diagnosis of PNE in June 2002. This was after extensive self-directed research and countless MDs refused to read, research, or even consult with the PNE experts on my behalf. They ignored the PNE diagnostic criteria that I gave to them and diagnosed me with an unfounded and untrue ‘masked clinical depression’ and believed that the etiology to my excruciating pain was psychogenic rather than neurogenic.

I do have a list of recommendations for women seeking assessment for pelvic pain, such as always bring a spouse, partner or friend with you into the exam room, so there is accountability via a witness for the words spoken and questions asked. Always ask at the beginning for a copy of the visit summary to be sent to you, so they know you will be reading their words. The final draft cannot be altered, but any errors can be corrected per corrective addendum requests in writing. It is a powerful tool to protect your good name and character on paper, your legal medical documents that precede you to the next MD.

Kathy

Kataween53@comcast.net

DES Action Exhibits at the California Governor's Conference for Women

By Patti Negri
President, DES Action

ON December 7th, more than 10,000 women gathered for the 18th annual California Governors Conference for Women. I was privileged to represent DES Action as an exhibitor at this sold-out event.

This year's theme was *Women As Architects of Change*. Inspiring speakers and presenters represented close to 100 diverse and prominent national leaders in their fields. Her Majesty Queen Noor of Jordan and Linda Ellerbee, an award-winning journalist and bestselling author, served as keynote speakers. The day also included Gayle King, the editor of *O Magazine*; Jamie Lee Curtis, acclaimed actress and author; Dr. Wayne Dyer; and Meg Whitman, president and CEO of eBay, to name a few.

As all of the sessions and presentations were going on throughout the massive Long Beach Convention Center, there

was a constant stream of women to our DES ACTION information booth. My co-volunteer and local L.A. DES Action member Marilyn Shenker and I had the opportunity to meet and talk to some really wonderful women throughout the long and exciting day. Women of all ages were very interested and open to hearing about DES. One of the first

women I encountered was a medical doctor. She was an OB GYN who was totally unaware and surprised by the DES information. Coincidentally, she said that just the week before, she and a colleague were wondering why the "Are you DES exposed?" question is still asked on patient questionnaires! I explained to her why it was still pertinent to know of exposure in all stages of life, including mid-life and transition



Enthusiastic DES Action volunteers Marilyn Shenker and Patti Negri.

stages, which a lot of DES exposed women are entering into. I also told her about the possibility of third generation effects. She was amazed. She is now going to research the subject, starting with the CDC's DES Update website for MDs! We spoke with a lot of DES daughters, and many, who hadn't thought or heard about it in years were very interested in the new information and findings. TONS of possible third generation young teens were eager to find out more, too! We had a little help from "DES exposed Barbie" and "Dr. Ken" to bring people in to our booth and get the conversation started (works every time!) We handed out lots of DES Action brochures and information as well as info from the CDC's DES Update.

The event ended with a moving and empowering presentation by Oprah Winfrey, and a "Remarkable Woman" concert by Sheryl Crow. It was a great day for women. It was a great day for DES Action.

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the next time. For more about this book, readers can go to the author's web site,

www.comingtoterm.com

Our Bodies, Ourselves. The Boston Women's Health Book Collective. Simon and Schuster, 2005.

First published 35 years ago, this is the eighth edition of a unique reference book for women of all ages. When it came out in 1970, self-published on

newsprint by the Collective, it was a welcome source for important information. But, as the editors write,

"And now? We are bombarded with marketing ploys about 'what to use and how to feel' by drug companies and others trying to make a profit. But are decisions any easier to make? How can we know if our sources of information are reliable? What are the true risks of new drugs, devices, and

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A New Way to 'Talk' to Each Other

HOW would you like to communicate with other DES Daughters and Sons? Perhaps you're wondering about something and want to know if others have had the same experience? Maybe you need support from someone who's been there. Could you benefit from a free flowing exchange of personal ideas about DES exposure?

With members living around the country we can't pull together a huge in person meeting—so the next best way to "talk" to each other is via the internet.

DES Action has established two separate members-only listservs—one for **Daughters** and the other for **Sons**.

There is a demonstrated need for a forum allowing Daughters to communicate with each other. We also believe the time is right for Sons to have this same opportunity for conversations about their own special issues.

Down the road we figure another listserv for 3rd Generation DES exposed will be next. We'll get the first two up and running and then expand.

A listserv is a system where a group of people can communicate with each other via email. There are thousands of listservs around the world, most offering support and information to people who have something in common.

DES Action's members-only listserv has been established with Yahoo. Users of other Yahoo Group listservs say they are very happy with the service—which was set up with maximum security and privacy in mind. Only DES Action moderators will be able to see the names and email addresses of participants.

When you join a listserv, you participate in an email community. Just send an email message to the listserv and it is automatically distributed to all members of the group. In this case that means only those who have signed up for the listserv—not every DES Action member.

Messages others send to the group will automatically come to your email inbox, as well as to everyone on the listserv. If you reply to a message, your reply will automatically be distributed to everyone in the group. It makes for interesting, supportive and informative dialogue.

JOINING IS EASY

It is a two-step process:

1) To join the DES Action Daughters listserv simply send an email to: DESActionDaughters-subscribe@yahoogroups.com
To join the DES Action Sons listserv simply send an email to: DESActionSons-subscribe@yahoogroups.com

No need to put anything in the subject line of the email you send. Don't even bother typing a mes-

sage. By sending a blank note to the appropriate email address you have initiated the process.

In a few minutes you'll get an email back from Yahoo! Groups—asking you to confirm your request to join the listserv. It offers you two ways to register for the DES Action listserv you've selected.

2) The easiest is to select option 2, which has you click "Reply" to the message you are reading—so you send the note back the same way you reply to any email. By sending the message back, you are confirming that, "yes," you want to join the listserv and the email address you are replying from is the one you want to use for this service.

Within several days, and probably sooner, you'll hear back from DES Action. After confirming your current membership status, the welcome letter will contain details on how to send messages to the listserv. Then, you can participate fully in the dialogue!

This is an exciting new benefit offered by DES Action that we hope will be fully utilized by our members. Come join us and let's learn and share together.

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medical procedures? ...The new edition covers every aspect of women's well-being, from nutrition and exercise to sexual health, child bearing, and menopause. It also addresses emerging issues in women's health, such as menstrual suppression, emergency contraception, female sexual 'dysfunction,' and direct-to-consumer advertising.... The book also includes many new personal experiences, including

women talking about sexually transmitted infections, reflecting on the loss of a newborn, and describing the ambivalent emotions that surround caring for an elderly parent with Alzheimer's.

"A new web-based companion to the book will ensure access to expanded, up-to-date content along with new web links. This website will launch with the book in May."

The web site address is www.ourbodiesourselves.org

Report on the Tall Girls

By Pat Cody

"Oestrogen treatment to reduce the adult height of tall girls: long-term effects on fertility," Alison Venn et al, *The Lancet*, 23 October 2004

THESE researchers have reported from time to time on estrogens, either DES or ethinyl estradiol, given to adolescent girls whose family (or the girl) were concerned about potentially tall stature. This experimentation, based on theory and not on fact, took place in Australia, the US and some European countries, starting in the 1950s.

Here we have the first study, done in Australia, on fertility in these women, now in their late 30s, comparing them (371) with women assessed for such treatment but not receiving it (409). The treatment began at an average age of 12.7 years for the DES-treated girls who received daily treatments for an average of 26.4 months.

Dr. Venn and her colleagues found that the estrogen-exposed women – both DES and ethinyl estradiol – had greater problems with fertility than the non-exposed women. Twice as many of the exposed had seen a doctor about infertility and over twice as many (18.3%) had

taken fertility drugs as the untreated group (8.3%). Final outcomes, however, were similar: 66.9% of the estrogen treated women had live births compared with 65.3% for the untreated women.

The authors note that "Although this notion provides some reassurance about fertility potential after treatment for tall stature, infertility treatment involves health risks and the financial and emotional costs are substantial for many women."

Dr. Venn writes that further studies on other possible effects will be done.

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1978-2005

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