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U.S. Supreme Court to Consider Limiting Pharmaceutical Lawsuits

By Aaron Levine and Fran Howell

A case going before the U.S. Supreme Court in October may have an enormous impact on whether individuals harmed by prescription drugs can file suit for compensation against the pharmaceutical companies who made the drugs. While not specifically

“We have every reason to believe that the currently configured Supreme Court is poised to strip pharmaceutical abuse victims of any recourse, under the guise of FDA omniscience,” says Attorney Aaron Levine

about DES, what the justices decide in the case will affect whether DES lawsuits can be filed. Attorney Aaron Levine fears the worst.

“We have every reason to believe that the currently configured Supreme Court is poised to strip pharmaceutical abuse victims of any recourse, under the guise of FDA omniscience,” says Levine. He is a Washington, DC, lawyer who handles numerous DES cases.

Lawsuits for injuries caused by defective drugs are traditionally heard in state courts using each state’s laws for negligence, misrepresentation, failure to warn of possible injuries, etc. For centuries, those legal standards have

held that compensation is appropriate for injuries caused by another’s wrongdoing.

Now the Supreme Court is being asked to decide whether those state laws should be pre-empted or overruled on the grounds that the federal Food and Drug Administration (FDA) regulates pharmaceuticals. Therefore, the argument is that if the FDA approves a drug as safe for use, then no state court or jury can second guess that FDA decision. An injured victim could not sue because the drug alleged to cause harm had already been deemed safe by the regulatory agency.

Recent cases before the high court show which way it is leaning. Riegel v. Medtronic, Inc. was filed after Charles Riegel was injured by the explosion of a Medtronic balloon catheter during heart surgery. His product liability suit against Medtronic was dismissed by a New York court. Riegel died before his lawsuit reached the Supreme Court. Medtronic had argued that since it had gone through the “pre-market approval” process as required by federal law, it did not have to comply with the general state law mandating that medical products must be reasonably safe, effective and properly

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No Overall Cancer Risk Shown for DES Grandchildren

Specifically: Ovarian Cancer May Be Of Concern

“Offspring of Women Exposed in Utero to Diethylstilbestrol (DES): A Preliminary Report of Benign and Malignant Pathology in the Third Generation,” Linda Titus-Ernstoff, et al, *Epidemiology*, Vol. 19, No. 2, March 2008.

Reviewed by Fran Howell

This research is encouraging in that it indicates no increased cancer risk for the children of DES Daughters, save for one type of cancer, ovarian cancer, with the possibly

heightened risk for it needing further study.

Done as part of the National Cancer Institute (NCI) DES Follow-up Study, Principal Investigator Linda Titus-Ernstoff, PhD, a Professor at Dartmouth Medical School, and her team evaluated cancers occurring in DES Grandchildren. The data came from two sources. First, DES Daughters and a control group of unexposed women participating in the DES Follow-up Study were asked to report cancers in their sons

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I am a: DES Daughter DES Son Other DES Granddaughter or Grandson
 DES Mother of a: Daughter Son

NAME _____

ADDRESS _____

CITY | STATE | ZIP _____ PHONE _____

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Join OnLine Support Group for DES Daughters

Want to be in touch, via e-mail, with other DES Daughters? As a benefit of being a DES Action member you can join the DES Action Daughters On Line Support Group. That way you can ask questions and share experiences common only to those of us who are DES exposed.

To join the DES Action On Line Support Group simply send a blank e-mail to: DESactionDaughters-subscribe@yahoogroups.com

You'll receive an e-mail back from Yahoo! Groups confirming your request to join. It offers two registration options and the easiest is Option 2. Click "Reply" so the note is sent back.

Once we've checked to be sure you are a current DES Action member, you'll receive a welcome to the group letter explaining how to send messages. Then you can participate in the e-mail conversations, or just quietly read and enjoy the learning experience.

MISSION STATEMENT

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



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DES Grandchildren *from page 1*

and daughters. Second, 793 granddaughters (463 exposed and 330 unexposed) were asked to self-report their own cancer diagnoses as part of this Third Generation Study. Cancers reported by the second group were verified with medical records.

The researchers were particularly interested in the incidence of cancers in the exposed group because laboratory studies show that DES grandchildren mice exhibit an elevated

This finding is of concern because an increase of reproductive tumors is seen in DES-exposed granddaughter mice in laboratory studies, and mouse studies have been good predictors of what might happen in human populations.

incidence of reproductive tumors.

However, in this first evaluation of human cancers, Titus-Ernstoff says, "Our data do not support an overall increase of cancer risk in the sons or daughters of women exposed prenatally to DES." But she goes on to add, "The number of ovarian cancer cases was greater than expected."

While no ovarian cancers were found in the unexposed group, a total of three ovarian cancers were found in the DES Granddaughters. Two were self-reported by Third Generation Study participants and were confirmed by medical records. One of these was diagnosed at age 22, while the other ovarian tumor, which had metastasized to the lymph nodes, was diagnosed in a 20-year old. A third ovarian cancer among DES Granddaughters (juvenile granulosa) was diagnosed at age 7. Because of her young age she was not part of the Third Generation Study, so her diagnosis was not verified using medical records. According to Titus-Ernstoff, three ovarian cancers in this size group were more than what was expected based on general population statistics. This finding is of concern because an increase of reproductive tu-

mors is seen in DES-exposed granddaughter mice in laboratory studies, and mouse studies have been good predictors of what might happen in human populations.

As for other results, there was no increase in testicular cancers for DES Grandsons nor were there any vaginal/cervical clear cell adenocarcinomas (CCA) among the DES Granddaughters. Also not found were any breast cancer cases, however the researchers suggest that participants are too young for a meaningful assessment of that cancer right now.

Because this was a small study, and participants are still young in their reproductive lives, Titus-Ernstoff warns that it is simply too early to say with any certainty that DES Grandchildren have little to fear in the way of increased cancer risks resulting from their exposure. While the results are encouraging, she says the incidence of ovarian cancers, coupled with what is known about tumors in exposed laboratory mice, supports further study and health monitoring of DES Grandchildren as they age.

DES VOICE



Celebration! Save the Date!

Plans are in the works for DES Action's 30th Anniversary Celebration this fall. Details are being finalized, but we can tell you this much:

Date: Saturday, September 20, 2008

Where: New York Firehouse Museum
(in the SoHo District of Manhattan)
278 Spring St.

New York, NY 10013

<http://www.nycfiremuseum.org>

The non-profit museum has generously offered to allow DES Action celebration attendees to tour the fire museum's extensive exhibits without charge—and they are well worth seeing!

Please watch for more details in the DES Action *Voice* newsletter Summer Issue, which goes out in August. We'd be thrilled to have as many members as possible join us for this exciting event.

OVARIAN CANCER SYMPTOMS

It is not easy detecting ovarian cancer and females of any age can be diagnosed with it. But for the most part, it is a disease of women past menopause. According to the American College of Obstetricians and Gynecologists (ACOG), ovarian cancer is not commonly found in women younger than 40.

As a result, doctors may not suspect this cancer in younger patients. So those of us in the DES community might want to pay attention to symptoms in DES Granddaughters. However, as researcher Linda Titus-Ernstoff stresses, the number of cases identified in her study was very small and it is too early to know yet whether this group is actually at increased risk.

The web site, www.mayoclinic.com, explains that ovarian cancer symptoms are vague

and mimic those of other common conditions, especially digestive and bladder disorders. "With most digestive disorders, symptoms tend to come and go, or they occur in certain situations or after eating certain foods. With ovarian cancer, there's typically little fluctuation — symptoms are constant and gradually worsen."

- persistent abdominal pressure, fullness, swelling
- urinary urgency
- pelvic discomfort or pain
- persistent lack of energy
- increased abdominal girth
- lower back pain

Because these symptoms are generic, in most cases they will not result in an ovarian cancer diagnosis. Still, if they persist and worsen, they should be brought to the attention of a doctor.

DES VOICE

DES ACTION

In the history of DES Action the name of **NORA CODY** is connected with the significant national research and education advocacy accomplishments of the organization. As Executive Director for almost fifteen years from early 1990 through 2004, she initiated program ideas and shepherded the outcomes of the Research and Education Amendments of 1992, which paved the way for continued Congressional funding of DES research and for the CDC's DES Update for health professionals and consumers in 2003. Remembering that DES exposure affects families, Nora Cody is the sister of a DES Daughter. Her compassion makes her a DES Sister to all of us.

*Kari Christianson
DES Action Program Director*

I first met **LIBBY SAKS** back in the mid 1980's when I began my involvement with DES Action. I was new to the organization when I shared my medical history with her, and she was very supportive and empathetic. I had just learned about being a DES Son after my diagnosis with testicular cancer. As our friendship grew, this DES Action Co-Founder and well-respected past Board member shared with me how it feels to be a DES Mother, which helped me understand what my mother must be going through. Libby helped the Board with many of the tedious details of setting up meetings in the New York area. She, and her husband Mort, were instrumental in getting numerous grants that enabled

DES Action to move forward with its educational activities.

*Michael S. Freilick
DES Action Board Member and
Director of the DES Sons Network*

JOHN MCLACHLAN'S early interest in the role of estrogens guided his pioneering work with DES-exposed laboratory mice, revealing many of the abnormalities later seen in humans exposed to DES. Over John's 21 years at the National Institute of Environmental Health Sciences, during which he rose to become Scientific Director, he maintained a steady focus on estrogen. Early in the life of DES Action, John invited me, as a consumer advocate, to the first Estrogen in the Environment conference in 1979 to make a poster presentation to researchers. In 1995 he became Director of the new Center for Bioenvironmental Research at Tulane and Xavier Universities. In 1997, when *Newsweek* listed him as one of "100 people to watch as America moves into the next millennium," he initiated the Environment and Hormones web site (e.hormone.tulane.edu), a clearinghouse for all things related to endocrine disruption, a true "laboratory without walls." John's brilliant mind and creative energy are reflected in his many contributions to our understanding of the world around us.

*Pat Cody
DES Action Co-Founder*

The news in December 1977 linking DES exposure to a greater risk for breast cancer in DES Mothers led **CYNTHIA LAITMAN**, medical writer and mother of 8-year old Kate,

We continue our 30th Anniversary celebrating the individuals who've helped us through their noticeable impact by giving both time and talent.

This is part two of our four part series celebrating people whose work has been integral to our success that no one on this list thinks of her or him as each one is to DES Action.

Some on this list are no doubt familiar names described from time to time in the VOICE that is the foundation of our organization.

These short profiles clearly cannot encompass the contributions made by these special people. Please reflect on all that has been accomplished, in, and for, the DES community.

to begin her life-long activism on DES. Her 1982 book, *DES: The Complete Story*, received the Morris Fishbein Award for Medical Writing from the American Medical Writers Association. In 1993 Cynthia initiated

the Wisconsin DES study as part of a five-center program from the National Cancer Institute. She also worked on educating physicians with a chapter on "Effects on men of prenatal exposure to diethylstilbestrol" in the book *Infertility in the Male* published in 1997. Other publications include articles on DES in the *Scientific European* (1990), *Current Women's Health Report* (2002), and *Journal of Midwifery and Women's Health* (2003). Cynthia is a founding Director of TeleTruth Wisconsin, an alliance of public interest groups promoting affordable telecommunication services.

*Pat Cody
DES Action Co-Founder*

ON HEROES

...bration with another look at some of
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...compass the full scope of contribu-
...lease enjoy reading about them and
...plished through 30 years of working

Thousands of DES Daughters and Mothers know **CANDY TEDESCHI** as their extremely caring and knowledgeable health care provider. What they may not realize is that through countless speaking engagements, teaching opportunities, media interviews, service on numerous professional committees, as well as contributions to books and professional publications, Candy has enlightened many thousands of her colleagues, and the public, about health effects and proper treatment for DES exposure. From 1981-1999, Candy served as Nurse Coordinator for the DES Screening Center at Long Island Jewish Medical Center. She continues caring for DES Daughters while traveling and educating medical professionals. Candy currently serves on DES Action's Board of Directors and works as Director of Colposcopic Services for Brookdale Medical Center in Brooklyn. She is

the health care provider and leader we wish for all DES-exposed women.

*Nora Cody
Former DES Action Executive Director
and Board Member*

NANCY HERSH'S DES litigation goes back to the early days when drug companies were still claiming that DES was "safe and effective." As part of our advocacy work, we were approached by lawyers who first heard about DES from Daughters seeking help. Nancy created our Legal Packet, over 300 pages of basic information about DES, existing law on product liability, and court decisions in several states. This publication, which we sold to lawyers, helped keep us going in those years. Nancy has worked on many DES cases, bringing millions of dollars to DES Daughters with cancer and infertility linked to exposure. Taking drug companies to court continues to be the focus of her practice, creating a larger good by removing dangerous products. This kind of legal work is critically important in providing incentives for proper testing of new drugs and procedures.

*Pat Cody
DES Action Co-Founder*

The first time I saw **ANDREA GOLDSTEIN** she was waving an x-ray of her T-shaped uterus at a DES Task Force meeting in Washington. As a DES Daughter with infertility problems, she was angry. Andrea turned that anger into activity by running the Boston Chapter of DES Action while also volun-

teering for DES Action National. She served as a DES consultant to the state Department of Public Health and was a member of the DES Action Board of Directors for more than a decade. In 1985, Andrea filed the first DES infertility lawsuit. That case, against Eli Lilly, paved the way for other DES Daughters experiencing infertility. She tirelessly fights to get the DES issue covered by the media and has recently been in touch with screenwriter Caitlin McCarthy, to share her historical perspective on the DES story.

*Libby Saks,
Co-Founder of DES Action
and longtime Board member.*

There are few claims to fame for a DES Daughter, but saying, "My doctor is Ken Noller" is one that counts. For over 30 years **KENNETH L. NOLLER, M.D.**, has been studying and reporting the effects of DES exposure as a Principal Investigator with the DESAD (National Combined Diethylstilbestrol Adenosis) Project and now with the National Cancer Institute DES Follow-up Study. This noted clinician and educator is the Louis E. Phaneuf professor and chair of the ob-gyn department at Tufts University in Boston. He currently is the President of the American College of Obstetrics and Gynecology (ACOG). Just as important to a DES Daughter, he is a doctor who listens and understands.

*Kari Christianson
DES Action Program Director*

DES VOICE

labeled.

The Supreme Court agreed with Medtronic, eight to one. Justice Antonin Scalia, writing for seven of the justices stated, “One would think that tort law, applied by juries under a negligence or strict liability standard, is less deserving of preservation.”

Levine explains that in Scalia’s view, “the FDA is more likely to balance the good against the bad, while juries see only the bad. It is clear the justice holds that victims of FDA-approved devices are not entitled to their day in court.”

The highest court in the land has already ruled in the field of medical devices. Drug lawsuits are likely next. In fact, the Supreme Court narrowly averted such a ruling in a case earlier this year.

In Warner-Lambert v. Kent, a lawsuit over liver damage caused by Pfizer’s diabetes drug, Rezulin, the ruling hinged on Michigan law. It bars lawsuits against FDA-approved drugs unless the drug company misled or bribed the FDA. Pfizer said that only the FDA should be able to determine that it was misled. The decision was four to four, with Chief Justice John Roberts abstaining because he owned Pfizer stock.

Since Roberts was appointed by President Bush, he is expected to follow the Bush Administration’s tenets that FDA approval of a drug as safe means it is safe.

According to Levine, “If Justice Roberts had been able to participate, his vote likely would have meant a Supreme Court ruling saying no evidence that the FDA was defrauded by drug makers, no matter how convincing, is enough to overcome the FDA’s own failure to act.”

Ruling Could Impact the Right of DES-Exposed to Sue

In October the case to be argued is Wyeth v. Levine (no relation to Aaron Levine). Musician Diana Levine claims she lost her arm after receiving an anti-nausea drug by an off-label

intravenous method because Wyeth failed to warn that using its drug that way could cause gangrene. She won a large verdict in the Vermont courts, but Wyeth has appealed to the Supreme Court.

Wyeth argues that since the FDA did not ask for that warning on the label, a jury shouldn’t be able to decide that Wyeth should have put it there. But the plaintiff maintains that when assessing the drug, and its labeling, the FDA did not even consider warning against the procedure that caused her injury.

“The fact that the FDA is far from omniscient will probably not sway the Supreme Court from holding that the FDA is the final arbiter of whether a drug is acceptably safe,” attorney Levine explains.

In this context, since the FDA approved DES, it doesn’t matter that the FDA later warned against its use for pregnant women. It also doesn’t mat-

ter that the wrongdoing of DES manufacturers has been shown time and again in court. What matters to the Justices is that when DES was prescribed it was FDA approved.

“For the current Supreme Court that is evidently enough,” says Levine, who warns, “if the ruling is that FDA approval preempts state common laws, then DES victims will lose their right to seek compensation in court. It is that serious.”

But, it should be noted, he adds, “that some of the justices have voiced an opinion that there could be two rules, one for drugs which have been recalled and another for drugs that are currently approved. DES has been recalled for all purposes and is no longer approved for humans. Therefore, there is room to hope the Court will take FDA recalls of bad drugs into account when deciding whether to ban lawsuits involving FDA approved drugs.”

DES VOICE

DES Research Links Smoking While Pregnant To Earlier Menopause In Offspring

Smoking May Affect Hormonal Environment of the Womb

“The Association between In Utero Cigarette Smoke Exposure and Age at Menopause,” William C. Strohsnitter, et al, *American Journal of Epidemiology*, Volume 167, Number 6, March 2008.

Reviewed by Kari Christianson

Cigarette smoking by women has long been linked with an earlier onset of menopause. But researchers were interested in finding out if smoking by a pregnant woman could influence the age her daughter entered menopause.

This study led by William C. Strohsnitter, D.Sc., of Tufts Medical Center and a Co-Principal Investigator with the National Cancer Institute DES Follow-up Study, analyzed menopause information gathered

over 30 years from women in the Daughters’ Cohort of the DES Follow-up Study. Mothers of these women were asked about their cigarette smoking during pregnancy. The active smoking history was also asked of DES Daughters and unexposed control participants.

The findings suggest that “prenatal exposure to maternal cigarette smoke may affect the age at menopause for female offspring,” particularly among women who have never actively smoked themselves. This confirms other studies which have shown that a mother’s smoking changes the hormonal environment of the developing fetus, which can possibly affect a female offspring’s reproductive lifespan by interfering with the number of ovarian follicles produced before birth.

continued on page 7

The DES Story Comes Alive in a New Book

**Reviewed by Fran Howell
and Kari Christianson**

It's been a long time since a new book has been published regarding the DES tragedy. DES Action Co-Founder Pat Cody, at the epicenter of consumer activity for more than 30 years, has taken up the challenge and written our story—a saga of our DES experiences.

The title tells it all. *DES Voices: From Anger to Action*, and each of us can understand it.

Cody, a DES Mother herself, included many of the voices important to our struggle: DES Daughters, Sons, Mothers, Fathers, Attorneys, Researchers and Clinicians.

She describes how DES, an easy to manufacture synthetic hormone, was promoted to doctors for use with problem pregnancies. Greedy drug companies even urged doctors to prescribe DES for all pregnancies to ensure healthy babies—long after DES was proven ineffective.

As cancers and later infertility and other reproductive problems were

linked to DES exposure, there was a frightful lack of information for those who needed it most—the mothers and children who were just learning about their exposures.

In pre-Internet America, phone calls, flyers and hastily called meetings mobilized the concerned. Groups sprang up in far flung cities around the country, eventually coalescing into the DES Action organization that has been at the forefront of this issue ever since.

Throughout the book, Cody includes correspondence and transcripts of events as they unfolded. In reflecting on the importance of understanding the health effects of DES exposure to society as a whole, she says, “the dying swans and gasping fish cannot speak of their sufferings, but humans affected by chemicals can be eloquent, as the letters of this book show.”

DES Voices is the amazing story of how a small group of determined individuals accomplished so much with so little. Even now, DES Action is considered a model of an effective grassroots consumer organization because of the passion and energy that

generated Congressional hearings, followed later with funding for DES research and educational campaigns. This is a story of which we can be proud.

 **DES VOICE**

To order a copy of *DES Voices: From Anger to Action* send \$12.95 for each book (which includes shipping) to: DES Action, 158 South Stanwood Rd., Columbus, OH 43209. Don't forget your name, mailing address and contact information in case we have a question about your order.

Smoking from page 6

As reported in VOICE 110, a previous research study found that DES Daughters may experience a slightly earlier natural menopause. That finding pertained to women exposed prenatally to higher cumulative doses of DES and did not address maternal smoking.

Another interesting, but confusing, finding of this study was that the “well-documented association between active smoking and age at menopause was **not** present among women prenatally exposed to maternal cigarette smoke.” In this study DES Daughters exposed to their mother's cigarette smoke before birth and who also smoked did not experience an earlier natural menopause than women who were exposed to

maternal cigarette smoke but did not smoke themselves. Future studies may provide more answers about the age of menopause, higher cumulative doses of DES, maternal smoking during pregnancy, never smoking and active smoking for DES Daughters and all women.

The extensive health history information gathered for the National Cancer Institute DES Follow-up Study offers researchers the opportunity to use these cohorts for answers to developmental environment questions, some of which are seemingly not directly related to DES exposure outcomes. However, understanding the mechanisms of fetal development and the vulnerable prenatal environment has long been a way DES research serves society as a whole.

 **DES VOICE**

Letter To The Editor

I want to thank you for your article, “DES Action Heroes.” I had the good fortune to meet Fran Fishbane more than once. I attended a meeting in the '70s, held in a restaurant, with Barbara Seaman, Fran and others. There, for the first time, I met other DES Mothers and Daughters.

I myself am a DES Mother who was counseled by Fran Fishbane. My daughter was a regular patient at the DES Screening Center under the wonderful care of Dr. Krumholtz and Candy Tedeschi. They all made a difficult situation more bearable. I thank them, and DES Action, of which I have been a member since its inception. Keep up the good work.

Irene Shomberg, Forest Hills, NY

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Remembering a Renowned Women's Health Advocate

By Pat Cody

One of our heroes passed away in February at the age of 72. Barbara Seaman was the first medical writer to reveal the DES story in her 1977 book *Women and the Crisis in Sex Hormones*. She devoted the entire first section to DES—six chapters—before moving on to discuss problems with the pill, and, in one of the earliest warnings, the possible dangers of hormone replacement for menopause symptoms.

Barbara Seaman

Seaman's concern with women's

health was life-long and she helped found the National Women's Health Network (NWHN). In 1978, just after Sidney Wolfe, M.D., revealed the first study on a greater risk for breast cancer among DES Mothers, Seaman went to Washington with Fran Fishbane, an early Co-Founder of DES Action. They, and Dr. Wolfe, went to Secretary of HEW Joseph Califano to insist that federal health officials study DES. The Federal DES Task Force included them as members, in one of the first examples of consumer advocates participating in federal action on health concerns.

During a 2005 speech sponsored by DES Action, Seaman warned

against blindly taking prescriptions. She suggested checking drugs on reliable Internet web sites and using a healthy dose of skepticism when visiting drug company sites. There, she said, they promote drugs and seriously downplay negative research.

Cindy Pearson of the NWHN writes of "Barbara's best qualities and values – dogged determination to see medical abuses corrected, unwavering insistence on listening to women, and fearless willingness to challenge medical authority."

As one of the strongest voices for women's health, Seaman often used the DES saga as an example of drug company malfeasance. She is certainly missed.

 **DES VOICE**