V O I C E

A FOCUS ON DIETHYLSTILBESTROL

Summer 1990

#45

Good News on Law Suits

n the first trial in northern California of a DES-related case, a "substantial" out of court settlement has been won for Nancy Wheeler, a DES daughter who developed clearcell cancer in 1971. The suit is of special interest because the identified manufacturer, Boyle and Co., initially offered no settlement and so there was a seven week trial which went to the jury on June 14. After two days of deliberation, the defendants requested settlement negotiations, which concluded on June 15.

The interest in this case, and probably the reason Boyle did not offer settlement earlier, lies in the decision by the California Supreme Court in March 1988 (DES Action VOICE #36, Spring 1988) restricting the grounds on which people injured by prescription drugs can sue. Nancy's attorneys, Hersh and Hersh, were not able to sue Boyle for liability for defective products

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and breach of warranty. They were held to a much narrower ground of fraud and negligence, and based their \$3.3 million suit on those grounds.

Evidently Boyle thought that on these grounds Ms. Wheeler would not be able to succeed with a jury. However, the length of time the jury stayed in deliberation led to the conclusion that they might well vote for the plaintiff, so Boyle then asked to settle. And this conclusion was correct: jurors later told Mr. Hersh that they had agreed that Boyle had been negligent, and had committed a fraud by concealing a material statement of fact. Under California law, fraud must be determined by clear and convincing evidence.

This outcome will have an impact on the hundreds of cases now awaiting trial or settlement; it shows that juries do believe that our injuries are the responsibility of the drug companies and that we will be compensated.

Some other major victories in legal action occurred earlier this year, in New York and in Arizona. In the New York case, the five-member Appellate Court ruled by 4-1 that nine year old Karen Enright could sue the drug companies. Karen's cerebral palsy was caused because of birth trauma attributed to uterine deformities in her mother, a DES daughter. The court ruled that "Although (Karen) is not a DES



Nancy Wheeler

daughter, she may be no less a victim of the devastation wrought by DES than her mother, who is a DES daughter, and we see no sound basis for denying plaintiff her day in court along with her mother....To insulate the drug manufacturers by creating an arbitrary generational limitation on the legal responsibility for birth defect caused by DES...would serve only to dilute the economic incentive to turn out safe products."

A second victory, also in a cerebral palsy suit, took place in Arizona. Here the case brought by Christy Morrison on behalf of her seven-year old daughter Kristen was settled out of court in April for well over \$1 million. to provide for Kristen's care.

Get Into Action

DES Action USA could not have originated and grown without the dedicated efforts of volunteers. Today, we proudly boast the activities of over forty DES Action groups across the country and around the world. The foundation of each group was created and nurtured by volunteers. We still need you. Write your group today. Offer your services for a few hours a week. Become a part of the action with DES Action.

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Dublin Conference in September

ur newest affiliate, DES Action/Ireland, will be launched at the 3rd European DES Network Conference in Dublin the weekend of September 14-16. Co-sponsored by the Irish Council for the Status of Women and DES Aktiegroep of the Netherlands, the conference will begin with a Symposium on September 14 for health professionals, DES exposed people, women's health and consumer organizations. Pat Cody of DES Action USA is to give a history of the DES Action movement. Other speakers will address the health effects of DES, the implications with regard to current prescription of drugs during pregnancy, and liability for drug-induced injury. The concluding speaker, Mary Banotti, a member for Ireland of the European Parliament, will talk about "Drug regulation in the European Economic Community: concern for the future".

Conference sessions on September 15 and 16 will be devoted to sharing information and developing strategies on a national and European level. Delegates are expected from Spain, France, England, Belgium, the Netherlands, Germany, and Canada.

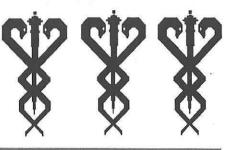
The DES Action Voice is published quarterly by DES Action USA 1615 Broadway, # 510 Oakland, CA 94612

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Printing: Inkworks, Berkeley, CA



Tell Your Children

Our New Campaign for the 1990s

f you're a DES mother and you're reading this, you've probably told your children about their DES exposure. But there are still hundreds of thousands of mothers who, because of a lack of information, guilt, or anxiety, have not shared this vital information. As the DES "first generation" grows older, this communication becomes more and more urgent. For mothers, telling your child is part of your care for that child. It is information that DES daughters and sons should have as part of their health history.

For years we have directed our attention to DES daughters and sons with the slogan "Ask Your Mother." Now, "Tell Your Children" fills in the missing half of the family equation. 1991 will be the year we launch the major media "Tell Your Children" campaign. We want to find a high profile honorary chair to represent this theme, ideally a celebrity over 50 and her daughter (or a volunteer stand-in). She need not be DES exposed herself. We want to film a public service an-

"For years we have directed our attention to DES daughters and sons with the slogan "Ask Your Mother." Now, "Tell Your Children" fills in the missing half of the family equation."

nouncement to be aired on TV stations throughout the country. This will cost about \$15,000, so you'll be hearing more about fundraising plans soon.

The "Tell Your Children" campaign fits in with the publication of our new booklet on Breast Cancer with its focus on that health issue for DES mothers. The campaign will also, of course, expand awareness and inform more daughters and sons.

The national office is working on finding a celebrity spokeswoman. If any of our members has personal contact with such a person, please get in touch with us.

Hope on Cerebral Palsy

e have news for cerebral palsy patients. The "Inside Edition" television program this spring featured two children of DES daughters, children whose cerebral palsy is a birth injury because of uterine deformities in their mothers.

Media attention always brings us many calls and letters, and this time one of them was from a mother with a cerebral palsy child. She wanted us to know about a relatively new surgical procedure called rhizotomy, which stops the spasticity in these patients. She said that her child's life was dramatically turned around by the surgery, and gave us the name and address of a self-help group that we then called:

Marion E. Say Rhizotomy Network Box 84455

Vancouver, WA 98684-0455 phone (206) 944-1178

Ms. Say said that her child was also remarkably improved and is now mainstreamed in school. The Rhizotomy Network has a \$15 packet of information that includes referrals to the surgeons who do this procedure, as well as material on the intensive physical therapy schedule that must follow the surgery since inactive muscles need to develop.

United Way For Us

Is there a United Way campaign in your workplace?

In most states you can now designate your preferred charity by requesting a "donor option card." If you choose DES Action, we will receive your contribution via the United Way.

Some companies also have a

"matching gifts" program and will match your contribution to a charitable organization. It's great to be able to "double your money" this way—and of course it's a big bonus for DES Action. Our thanks to all who take advantage of these workplace giving programs.

letters to the editor

Dear Editor:

As a 36-year old DES daughter and long-time subscriber to the DES Action VOICE, I have often looked to your newsletter for astute analysis, frank answers, and non-patronizing support around the many issues related to my exposure.

However, as a bisexual woman (who has chosen to remain childless), I have yet to see the kind of information in the VOICE that speaks specifically to the concerns of DES-exposed lesbians and bisexuals. Granted, the specter of infertility and its attendant technology, as well as issues associated with conception and heterosexual intercourse, are of paramount importance to a very significant portion of your readership. But for gay and bisexual women (and men) who by some estimates number upwards of 10% of the general population, particularly in large urban areas, we are often denied the access to essential information that comes with being a sexual minority.

Some questions that immediately come to mind for this group include:

Are there DES support groups specifically for gay and bisexual women?

What DES-related symptoms might we experience in the absence of—or perhaps because of—our engaging in sexual activity that does not usually include intercourse or use of contraceptives? (I have heard, for example, that adenosis is actually benefitted by the acidic PH of contraceptive creams and jellies.)

Who—and where—are the physicians and other medical practitioners who will be sensitive and knowledgeable about both DES and gender preference issues?

Finally, for DES-exposed women without regular male sexual partners who want to conceive through alternative insemination, what are their options?

Thank you for considering these very real and pressing concerns. I look forward to seeing the specific needs of DES-exposed lesbians and bisexuals addressed in future issues of the VOICE.

Janet Saevitz

Editor's note: Are there readers who can volunteer to help with such a support group? If so, please call or write the VOICE at our new office: 1615 Broadway, Suite 510, Oakland, CA 94612.

Dear Editor:

I have been through yet another ordeal as a result of DES. Last fall I went for my annual pelvic exam and Pap test to a new physician since I had just recently moved to this area. I thought since I hadn't had a colposcopy in many years that I should do this. When the gynecologist took a look she became very concerned. The Pap test caused lots of bleeding (and was not readable). She declared me to be "out of her league" and referred me to a "specialist", i.e. an ob/gyn oncologist, the "best in the city."

The "specialist" took one look through the colposcope and told me that I had adenocarcinoma of the cervix and ordered \$400 worth of biopsies etc. After I got dressed the doctor told me that a radical hysterectomy was recommended (I have had not any children yet) and I was sent home to wait a week for the lab results. The doctor had not a kind word for me that day. Somehow I made it home and worried my way through the terrifying next week.

The lab tests were delayed an additional day (they were redone because the doctor did not trust the initial outcome). Finally, the word—"NORMAL"! PER-FECTLY NORMAL! for all the tests. What had been seen were normal glandular cells from the inside of the cervix folded outward and visible on the outside of the cervix—a typical DES change, but normal for us.

This is a case in point that we DES daughters need to know what is normal *for us* so that we are not terrorized by inept medical "specialists." I have just been made aware of DES Action's M.D. referral program. What an excellent way of helping each other obtain quality medical care. I wish I had known about it earlier.

Good health to all of you. H.L.B.

Dear Editor:

Since I am a DES mother and had a mastectomy in March, I have a vital concern in two issues not being addressed:

Doctors who do NOT discuss with DES mothers the risks in taking hormones at menopause and

the failure of imaging centers to send copies of the written mammogram reports to the

continued on page 7

A Little Legalese

by Cecelia Volk, Coordinator, Brooklyn N.Y. chapter and May, 1990 graduate of CUNY Law School at Queens College, Flushing, N.Y.

ince many DES daughters have either filed a law suit, or are contemplating doing so, it will be helpful to become familiar with common legal terms that your lawyer will use. Just as it is essential to empower ourselves with medical knowledge when speaking with our health care providers, it is equally important to understand the legal process so that you may assist your attorney in presenting the best possible case. Always insist that your attorney explain, to your satisfaction, what s/he is talking about.

The following definitions are taken from the *Dictionary of Legal Terms*—A Simplified Guide to the Language of Law, by Steven H. Gifis and published by Barron's Educational Series, Inc. (1983), and *West's Legal Thesaurus/Dictionary* by William Statsky (1985).

ACTUAL DAMAGES: Losses from an injury that can readily be proven, such as medical bills. DEPOSITION: A method of pretrial discovery that consists of a stenographically (or videotaped) statement of a witness under oath, in response to an attorney's questions; with the opportunity for the opposing party, or her attorney, to be present and to cross-examine.

DISCOVERY/DISCLOSURE: Pre-trial procedures by which one party gains information held by the adverse party concerning the case.

INTERROGATORIES: Pre-trial discovery tool in which one party's written questions are served

on the adversary, who must serve written replies under oath. JOINT AND SEVERAL LIABIL-ITY: A type of liability which exists when an injured party has the option of suing one liable party separately or all liable parties together. Each wrong-doer is individually responsible for the entire judgment, and the person who has been injured can collect from one wrongdoer or from all of them together until the amount awarded is received by the plaintiff.

JURISDICTION: The power of the particular court to hear a law suit. The Family Court could not hear a case involving a car accident.

MARKET SHARE THEORY: Each drug company will be responsible for the percentage of the market it held at the time the drug was sold. Thus, if company X had only 50% of the market and the plaintiff was awarded \$100,000, company X will only be required to pay \$50,000.

NEGLIGENCE: Failure to exercise a degree of care that a person of ordinary prudence (a reasonable person standard) would exercise under the same circumstances. Conduct that falls below the standard established by law for the protection of others against unreasonable risk of harm.

PRECEDENT: A prior decision that serves as an example or authority for resolving an identical or similar case.

PUNITIVE DAMAGES: Compensation in excess of actual damages that is a form of pun-

ishment to the wrongdoer.

STATUTE OF LIMITATIONS:
A law that fixes the time within which a party must take judicial action to enforce their rights. For example—you may have only 3 years to file a lawsuit after an injury resulting from a car accident. The statute can vary from one state to another.

STRICT PRODUCT LIABILITY: Liability without the need

STRICT PRODUCT LIABIL-ITY: Liability without the need to show fault, where an injury resulted from the use of a defective product.

summary judgment: A request that the court conclude there is no dispute as to any material fact and that a judgment be rendered without the need for trial. For example, company Y requests that the court grant a summary judgement because the plaintiff cannot prove she was exposed to DES.

THIRD GENERATION CASES (PRECONCEPTION): Children (DES grandchildren) having the right to sue for harm suffered as a result of parental reproductive injuries inflicted prior to their conception. This area is becoming very controversial and the courts have been reluctant to allow for this type of injury.

TIME-BARRED: Prohibited from filing a case because the statute of limitations has run out.

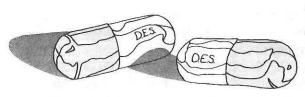
TORT: A civil wrong that has caused harm to person or property. In a civil trial, the standard of proof is a "preponderance of the evidence", which means that the evidence presented is more likely to be true than not to be true—or that it is 51% true.

TORTFEASOR: One who commits a tort.

JOINT TORTFEASORS: Those who act together (in concert) or continued on page 7

ANNOUNCING...

The First Comprehensive, Easy-To-Use DES Instructional Packet **Designed by Nurse Educators** for Nurse Education



Are you prepared to care for and teach your patients about DES? The Nursing Curriculum Unit on Health Care for the DES-Exposed Patient, developed for classroom or continuing education use, will prepare you. DES (diethylstilbestrol), a synthetic hormone drug given

to pregnant women from 1941-1971, affects over 9 million women and men in the United States. 50% of DES daughters will have some problem with their reproductive systems, including infertility, ectopic pregnancies, miscarriage and malformed uteri. DES daughters are also at risk for a rare cancer. DES mothers have a 44% higher risk for breast cancer, and DES sons may have fertility problems and are at risk for cancer.

DES-exposed people need special identification and care. You need to know how to identify and treat DES patients.

This 12-page unit (one-hour presentation time) includes information every nurse should know:

- Infertility and other effects of DES
- History and background of this drug
- ♦ Identifying the DES-exposed individual
 ♦ Special gynecological and health needs
 - Pregnancy care for DES-exposed women
 - How you can help your DES-exposed patients

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LETTERS from page 6... woman.

The U.S. Department of Health and Human Services states in their Breast Cancer Digest, "Malignant tumors often have irregular borders and/or contain clusters of minute flecks of calcium called microcalcifications. Larger calcifications, in contrast, are most often associated with benign conditions."

I have just discovered that in my 1986 mammogram there were unidentified clusters of micro-calcifications, yet my doctor made the decision that this report was not serious enough to warrant further investigations. Mammograms in following years were also filed away as I went along with the all too common arrangement—if you don't hear, all is well.

It was not until this year in January that a magnification view was called for by the imaging center where I obtain my mammograms. Still, both the radiologist and my doctor said all was normal in this view. I decided to obtain all my records and mammograms and go to the

Mayo Clinic in Jacksonville, Fl., where I am a resident. There they discovered not only a tiny lump but, in a biopsy, cancer. Fortunately it had not spread, but if in 1986 I had that written report, which I now know is sent to each doctor, I could have investigated further and obtained a second opinion. I would have taken action to be even more vigilant in my watch for breast cancer and I would have taken steps to lower my dose of estrogen and progesterone and perhaps eliminate them.

I am going to lobby so that every woman seeking a mammogram will obtain a copy of her written report, a report which in most instances today is not being given to the woman and winds up in the doctor's files. The information can alert the woman to any changes taking place in her breasts over a period of time and it could enable her to seek further information or a necessary second opinion. The imaging center says that technically the doctor orders a mammogram when the woman is his patient. I say if the woman calls for the

appointment, pays for the mammogram, and it is her body, she has a right to a copy of each written report and to that end I intend to get the word out to as many women as possible.

I really think we need to enter an era of "shared responsibility" not only for the patient's sake, but to narrow the margin of error. I hope you can get the word out to other mothers who have taken DES. All women would benefit by this dissemination of information which, I am finding, the medical establishment does not feel they need to share. My doctor actually told me most women don't understand that "medical jargon." I hope I can prove him wrong.

Marjorie L. Glazier

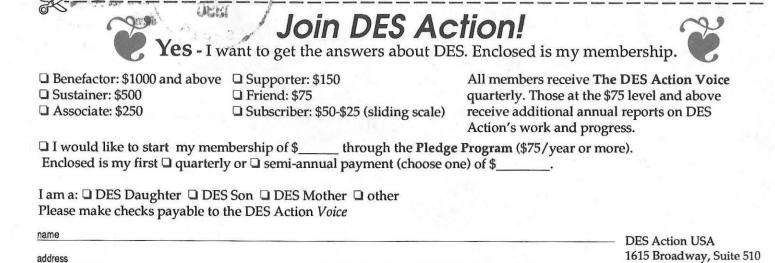
LEGALESE from page 5... independently to commit a tortious act.

MASS TORT: Large number of law suits filed as a result of injuries, for example, the Dalkon Shield cases.

TOXIC TORT: An injury caused by a toxic substance, such as DES or asbestos.

Oakland, CA 94612

(415) 465-4011



phone

* * dear doctor

I've been diagnosed as having a T-shaped uterus and my doctor tells me that this may make it more difficult for me to carry a pregnancy to term. Is there any surgery that can correct the T-shaped uterus so that it will function better?

Women who were exposed to DES in utero are at increased risk for a multitude of problems and deformities of the uterus. One such problem is a severe alteration in the configuration of the uterine cavity termed the "T-shaped" uterus. This anomaly is in the size and shape of the endometrial cavity, the site in

which the embryo implants and grows during pregnancy. The normal cavity is triangular in shape. In a "T-shaped" uterus the cavity resembles the shape of a "T" and the volume of the cavity is decreased.

Abnormalities of the shape of the uterus are associated with an increased risk of recurrent pregnancy loss. Some of these abnormalities are surgically correctable and include uterine septa (in which an extra portion of tissue occupies the middle of the uterine cavity) and bicornuate uteri (in which two equal uterine halves failed to unite during embryological development). Surgical treatment of these

anomalies results in a relatively normally shaped uterine cavity. This is possible because the tissue that is initially present allows for adequate reconstruction.

The underlying deformity of the "T-shaped" uterus precludes reconstruction that would result in a normally shaped and sized uterine cavity. Such surgery has not been recommended to treat infertility nor recurrent pregnancy loss in patients who were exposed to DES in utero.

Steven H. Brenner, M.D., F.A.C.O.G. Reproductive Endocrinology and Infertility Lake Success, New York

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