

## Jean Kasem hosts Fundraiser for DES Action

**D**ES Action received a significant boost to our Research Campaign when our national spokesperson, actress Jean Kasem, hosted a fundraiser at the Los Angeles estate she shares with her husband Casey and daughter Liberty Irene. The event, which was held on October 3rd, 1991, raised close to \$10,000 for our research campaign.

The evening, which was entirely underwritten by the Kasems, included speeches by Jean Kasem, DES Cancer Network member Pat Wyatt-Jose, attorney Roman Silberfeld, and Nora Cody.

Among those attending were Shadoe and Beverly Stevens and actress Valerie Harper, who not only contributed financially but looked for ways to help out during the party, pitching in with DES Action staff whenever needed.

At the event a number of DES Action members in the area met for the first time, and decided to begin to organize a new DES

Action chapter in Los Angeles.

Their first meeting will be held in February.

Jean Kasem's TV public service announcement has been shown in hundreds of cities in at least 35 states and we have heard from over 1000 people in response to its airing. Many callers say they had no idea about where to turn for information until they saw the PSA. Thanks very much to all of the members who made this project possible with your donations.

We are grateful to Jean Kasem



Casey Kasem, Jean Kasem, and Roman Silberfeld at the Kasem's DES Research Campaign fundraiser.

for her courageous and generous spirit. She has enlightened so many by sharing her personal DES story and she continues to play an active role in advocacy and awareness as she teams up with other DES Action members.

### DES in the Courts

## Record Award

**T**he largest compensation ever won by a DES daughter, an estimated \$4.25 million, was recently settled on 29-year-old Margaret Perrotte in a New York State court case. Ms Perrotte, who developed clear-cell cancer in 1989, sued a number of drug companies. Most of them settled out of court but the defendant with the largest share of the market, Eli Lilly, refused to settle and went to trial. The six-member jury had been prepared

to award \$2 mn. to Ms Perrotte for past medical costs, pain and suffering, \$550,000 to her husband, and \$200,000 a year for 51 years. Her attorney also planned to ask the jury for punitive damages, meant to deter future wrongful conduct, of the entire profits for one year of Eli Lilly, which would be over \$1 billion.

Facing all of this, Lilly was unwilling to gamble that an appeal would either reverse the

*continued on page 3*

### I N S I D E

*One Son's Story*

p. 3

*Notes From Nora*

p. 4

*DES and Human Rights*

p. 7

## 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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## ✍ letters to the editor

Dear Editor:

In reference to Dr. Glickson's letter in Issue 50, Fall 1991, I too had a hysterosalpingogram performed and was told it was normal. When going to another doctor I had a chance to view the picture. Even my untrained eyes could tell that my uterus was a text-book example of a T-shaped uterus.

M.S.

Dear Editor:

My HMO is still holding to the position that I have no need to see a DES specialist. Sometimes it seems that DES exposure and its consequences for me are not nearly so hard to adjust to in comparison with the bureaucracy, priorities and lack of concern of members of the medical and medical insurance professions. It helps so much to know that someone like you and your organization support my need for information, accurate diagnosis and confidence in that diagnosis. The treatment I have received from my HMO leaves me feeling as though I have no control over my own medical care and that my well-being is certainly secondary to their business practices.

S.F.



## Correction

Our front page photo in the Fall 1991 issue mistakenly identified the man with Harriet Simand. He is Warren Allmand, M.P. from Montreal.

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# One Son's Story

By Bill Kenny

I remember it like it happened yesterday. I was working out at the gym when I felt some vague discomfort in my testicles. Nothing serious, I thought. It'll go away. And sure enough, it did. But the pain came back a few weeks later, and this time I noticed that there was some swelling as well.

I had never heard of testicular cancer, so I assumed my problem was vascular, and would eventually go away. But when I talked to my sister long distance on the telephone, I mentioned the problem I was having. She was alarmed. She told me that she

was a DES daughter, and that I was probably a DES son. She also told me that she attended a DES support group. Some of the men in her support group had had testicular cancer. She urged me to call my doctor immediately.

Within twenty four hours, I was on the operating table. I remember being so scared at that point in my life. To me, cancer was a death sentence. I had so many questions, and no one to answer them. But then my sister put me in touch with the DES Action network. I called to tell them about my diagnosis, and they referred me to another DES

son who had also lost a testicle. It was such a relief to talk with someone who understood. And it was comforting to know that there was a reason why this had happened to me. That reason was DES. At least I knew what I was up against.

In the past year and a half, I have become a bit of an expert on the subject of testicular cancer. I know that it has a very high cure rate when caught at an early stage. I also know that many men are reluctant to talk about it, and delay seeking treatment until it is too late. I realize now how fortunate I am that my sister was aware of her DES status. If it weren't for her, I too might have waited too long.

I still have many questions about DES that remain unanswered. Unfortunately, there has been woefully little research done on DES sons. Although I subscribe to the DES newsletter, it rarely features a story like mine. I wonder how many men out there are unaware that they are DES sons. I wonder what future health problems I should be on the look out for. Obviously, there needs to be increased funding for research into the effects of DES on sons. Until then, we can only band together through the network and face our uncertain futures together.

## DES Sons Network

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Ed. note: *Men's Health*, a bi-monthly published by *Prevention* magazine, has a story on DES sons in their Feb. 1992 issue. This is the first such article on DES sons to appear in a popular magazine.

**COURTS** *continued from page 1* award or lower it, and decided to reach an agreement before the jury concluded its deliberations. Ms Perrotte was greatly helped in her suit by the changes in New York state product liability laws that DES Action members worked to bring about in 1986, and by earlier law suits that established the connection between DES exposure and clear-cell cancer. The suit therefore did not have to argue causation, but concentrated on damages.

## New Legal Approach on "Third Generation" Suit

Our Spring 1991 issue reported on a New York Court of Appeals decision that dismissed a "third generation" lawsuit, on the grounds that such suits would extend the liability of drug companies "beyond manageable bounds."

This November, a Maryland judge has allowed such a suit to

go forward, because attorney Aaron Levine framed his case differently. His argument was that a uterus is a shared organ. "It is not just the uterus of the DES daughter but of the granddaughter. Therefore an injury to the granddaughter's organ of birth constituted a personal injury to the granddaughter." In this case, the plaintiff, a DES daughter, delivered her child 13 weeks early. This DES granddaughter had a birth weight of 2 lbs. 7 ozs., and injuries to her vision, hearing, speech and development. The suit asks for damages incurred and to be incurred by the mother, on behalf of her child, for medical expenses, for vision, hearing and speech therapy, special training, and schooling until the age of 18.

The total sum requested from defendant Eli Lilly is \$1 million and the case will come to trial this summer unless an out of court settlement is reached.





## Notes From Nora

**I**n the last issue I told you about our trip to Washington, D.C. and our efforts to promote DES research in meetings with the National Institutes of Health (NIH) and on Capitol Hill.

In October we asked all of our members to mail letters to officials at the NIH and to Congresswoman Louise Slaughter. The response has been tremendous; Congresswoman Slaughter's aide told me that the hundreds of letters from DES-exposed people are "the most moving we have ever received."

Here are excerpts from just a few of these letters:

"I was exposed to DES in 1969 and 1970... The first pregnancy resulted in a miscarriage, but the second pregnancy resulted in the birth of my son. He was born with urinary problems and had to have his entire urinary tract reconstructed in two separate operations when he was two

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years old. It was extremely traumatic for the entire family and I later learned from my pediatrician that it was most likely the

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result of the DES that I had taken. I, myself, am affected with allergies every day of my life since I took DES, and have the additional fear of cancer."

—DES mother in New York

"My DES exposure occurred in 1953 when my mother was prescribed the drug during her pregnancy with me. She did not have a history of miscarriage but she did have a history of slight bleeding during her first trimester. At the age of 18, I was diagnosed with clear cell adenocarcinoma of my cervix and vagina due to my DES exposure.

Now, as I approach my 38th year I still fear this timebomb drug. I hear of other DES cancer daughters who are getting recurrences of their cancer 10 or more years past their initial diagnosis. No one seems to know how or why this is happening. I need to know what effect menopause will have on me as opposed to the non-exposed population. Should I take ERT or risk osteoporosis? These are just some of the questions that I need the answer to.

What scares me the most is that funding for DES research has all but stopped in recent years—the research centers that may have had the answers for me no longer have the funds to explore these questions. After having



Nora Cody, Executive Director, DES Action USA.

endured so much already must I still be victimized by the politics of research dollars?"

—DES daughter in Ohio

"I was exposed to DES in 1952 before I was born... Last month I underwent a cone biopsy and a complete hysterectomy. My conclusive diagnosis was squamous cell carcinoma in situ. I consider myself very fortunate because my awareness of my DES exposure resulted in early detection and treatment and did not allow the disease to progress to the life-threatening stages of invasive cancer.

...What I ask for is a chance to anticipate and prepare for the rest of my life...no one can predict the future as these (DES) children begin entering their forties and fifties. Many have suffered devastating consequences, including sterility and death. But many more, like myself, have been given a chance. Because of research, we have become informed and can take an active part in our health care. But we need continuing information....

But beyond DES mothers, daughters and sons lies a more compelling reason to support DES studies. Could the effects of this drug reach into future generations? This question has frightening implications, but we cannot afford to leave it unanswered. Nine years ago my youngest son was born with a genital abnormality. At the age of five he underwent successful corrective surgery. His condition occurs in the general population. However, according to the results of a 1978 study by the DES Task Force, DES sons are at increased risk for such abnormalities. My son's condition may be unrelated to my own DES exposure. No one would like to believe that more than I. But twenty years ago very few people anticipated or were prepared

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to accept the devastating effects of DES on a second generation. Without third generation studies, we can't know that the DES story will end with its daughters and sons. No one can correct the

terrible mistake nor erase the damage inflicted by the use of this drug. But we can offer the truth to future generations."

—DES daughter in California

If you have not gotten around to writing your letters, it's not too late. We need to keep our message in front of the people who are making policy. If you need to know where to send the letters, please drop me a note or call and I'll tell you.

I am very pleased to report that the NIH has set April 22-23, 1992 as the date for a special research conference on DES. DES Action will join researchers from a wide variety of fields in attending this important national meeting. The conference is expected to produce specific recommendations for research and for public outreach and education.

You can also expect to hear about a DES bill which will be introduced in Congress this coming year. We are working with Congresswomen Louise Slaughter (D-NY), Mary Rose Oakar (D-OH), Patsy Mink (D-HI), Rosa Delauro (D-CT) and others to draft a plan for a national public awareness campaign aimed at health care providers and DES-exposed people. We hope to persuade Congress to pass legislation which will mandate the most ambitious and comprehensive national awareness campaign ever. I will be writing to all of you as soon as the bill is introduced to ask for your letters and phone calls in support of this key legislation.



Response to our last fund-raising appeal, which asked for support for the DES Health His-

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tory Survey, has been overwhelming. We are so grateful to everyone who generously gave to make this important survey happen. Our goal in doing the survey is to learn about any special health problems which need research: information which will be just in time for the renewed interest in DES. Our last survey, in 1985, brought information about an impairment of the immune system which was confirmed in a more scientific study and reported in 1988.

We are working with scientists at Boston University's Slone Epidemiology Unit to draft the survey as a pilot project. The survey will be mailed to all of our members, as well as other DES-exposed people who have contacted us for information. The answers will guide a major study to be done in 1993. This preliminary study will be mailed to you in the beginning of March.

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# DES Use in Europe

**D**rugs travel across boundaries" is the theme of the first DES Awareness Week, to be held in Europe on April 6—12 this year. Our DES Action/Europe Network, made up of affiliates from France, Germany, Ireland, Italy, the Netherlands and the U.K., wants to put DES on the European agenda in the year when such significant changes as the Euromarket come into effect.

The need for awareness was clearly shown in a study done by our Dutch affiliate DES Aktiegroep.

Financed by Europe Against Cancer, a program of the European Commission, the study focussed on the extent of DES use during pregnancy in various countries. It also surveyed the interest among public health professionals in giving public and professional education about DES.

The report shows that DES has been on the market in all European Commission member states, as well as in other nations:

"Although most respondents do not know how much DES has been used in their country because no research has been done, they often state that DES was not prescribed widely in Europe compared to the U.S. They refer to the limited number of cases of clear-cell adenocarcinoma (CCAC) reported in the medical literature. However, under-reporting is likely because not every case of CCAC is recognized, particularly if no link has been made with DES exposure. Additionally, some cases may not be reported in the medical

literature. Benign abnormalities such as adenosis and pregnancy complications such as ectopic pregnancy, spontaneous abortion and premature deliveries are much more common side effects of in-utero DES exposure. Only a few respondents refer to these adverse effects.

"In the Netherlands, with a population of 15 million, 55 cases of CCAC has been reported. This is the largest number of cases reported in a European country. The second largest number of cases are in France, which has 12 cases reported in the medical literature and at least 20 known. It is not very likely that DES was prescribed more widely in these countries than in other European countries.

"It is more likely that the problem has become more visible because of awareness campaigns started by DES Action. As a result, doctors have become more informed and more sensitive towards recognizing signs of DES exposure and cases of CCAC.

"Moreover, the survey also shows that the majority of respondents found no information on the number of women exposed to DES in their country available in the medical literature or from their Ministry of Health. The majority also reported no efforts in their country to document the number of women exposed to DES by reviewing medical records or pharmaceutical industry sales figures for DES.

"The contradictory responses often received by different respondents from the same country also reveal the lack of reliable information available on the

extent of DES use. They indicate that more research is needed in most countries on the extent of DES use, and that information must be made available.

"This lack of information could discourage efforts by health organizations, public health agencies and individual physicians to tackle the DES problem in their countries. In addition, this missing information tends to produce a bias towards underestimation of the magnitude of the problem. This could hamper funding, for example, for initiatives to educate health professionals and the public about DES.

"Less than 20% of the respondents believe that information on the adverse effects of DES is available to the public in their countries. This result underscores the need to disseminate information about DES to the public.

"Finally, it is very important to education the public about DES. In the Netherlands and France it was initially believed that very few individuals had been exposed to DES. However, extensive public information campaigns, in which DES Action was involved, revealed that there were many more individuals concerned about possible exposure to DES than originally expected. Increased public awareness may also have contributed to the recent reappraisal of the number of people believed to be exposed to DES and to better medical care for exposed people."





## DES and Human Rights

**T**he Permanent People's Tribunal is an international forum of justice set up in 1977 for presenting and judging violations of human rights. The Tribunal, located in Rome, is the permanent successor to the Bertrand Russell War Crimes Tribunals on Vietnam and Chile. They have investigated major abuses of human rights, including hearings on crimes without penalty in Latin and Central America (Argentina, Guatemala, Nicaragua, El Salvador), the Philippines, Afghanistan and the International Monetary Fund and World Bank. Judgments from the Tribunal have been submitted to major international groups, including the UN Committee on Human Rights.

Last year they convened at Yale School of Law in New Haven for their first session on "Industrial and Environmental Hazards and Human Rights." After two days of testimony from people personally affected by hazardous technologies, the Tribunal found "clear evidence of gross violations of fundamen-

tal human rights by corporations and government agencies."

Amanda Sherman from DES Action testified at the Hearings on the consequences of DES exposure. She described the diverse health injuries suffered by DES mothers, daughters and sons. Problems concerning the medical community, government negligence and legal complexities were also outlined. In addition, the issue of manufacturers' culpability was examined. A list of over 200 pharmaceutical companies that manufactured DES was presented to the judges.

Testimony was also given by women who used the Dalkon Shield, people exposed to radiation from atomic testing and the mining of radioactive materials, workers suffering from asbestos poisoning, and Vietnam veterans exposed to Agent Orange. Victims of mercury poisoning from Minimata, Japan, traveled half-way around the world to tell their story; as did workers from Bhopal, India, who were injured in one of the world's worst industrial disasters—the acciden-

tal release of toxic gases by Union Carbide.

Unfortunately, perpetrators of human rights violations through industrial technologies all too often evade substantial accountability. Widespread lack of penalties increases the risk that others will be exposed to similar hazards. This is certainly true in the continued marketing of DES, especially in Third World countries where the laws are more lenient and where there has been no professional or public education about hazards.

The U.S. session of the Permanent People's Tribunal concluded by accepting a twelve-point charter of victim rights based on existing human rights laws, and urged that international standards for hazardous technology be strictly enforced.

The Tribunal also emphasized that a critical task before the international community is to expose violations of these rights and to insist that such violations cease. Future sessions of the Tribunal will address methods for holding corporations and governments publicly accountable for their actions.



## Join DES Action!

**Yes -** I want to get the answers about DES. Enclosed is my membership.

- ☐ Benefactor: \$1000 and above    ☐ Supporter: \$100  
☐ Sustainer: \$500    ☐ Friend: \$75  
☐ Associate: \$200    ☐ Subscriber: \$50-\$25 (sliding scale)

All members receive **The DES Action Voice** quarterly. Those at the \$75 level and above receive additional annual reports on DES Action's work and progress.

- ☐ I am enclosing my annual payment of \$ \_\_\_\_\_.  
☐ I would like to donate through the Pledge Program with ☐ quarterly or ☐ semi-annual payments totalling \$ \_\_\_\_\_.  
☐ Check enclosed (please make payable to: DES Action).

I am a: ☐ DES Daughter ☐ DES Son ☐ DES Mother ☐ Other

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state \_\_\_\_\_

zip \_\_\_\_\_

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## Hail and Farewell to Board Members

DES Action's Board of Directors said regretful goodbyes to three members who have done wonderful work over the years:

**Joyce Bichler**  
**Shirley Simand**  
 from DES Action/Canada  
 and our PR expert  
**Anthony Tedeschi**

Our new board members are all DES daughters:

**Linda Dozoretz**  
 Los Angeles, CA  
**Amanda Sherman**  
 Manhattan, NY  
**Cecelia Volk**  
 Brooklyn, NY

Their skills, energy and commitment ensure further success in our goals of public and provider education.

TELL  
YOUR  
CHILDREN

DES ACTION

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