DES *ACTION VOICE*

a focus on DIETHYLSTILBESTROL: a national issue

Vol. 1 No. 1
January, 1979
DES ACTION VOICE published by DES ACTION/N.Y., Inc. for DES ACTION National. Offices located at Long Island Jewish Hillside Medical Center, New Hyde Park, N.Y. 11040

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INTRODUCTION

This premier issue of DES ACTION VOICE is an important milestone in the growth of the movement towards public awareness about the health consequences of the use of Diethylstilbestrol (DES). This Newsletter is one tangible product of many individuals' dedicated efforts to make known on a national level the issues related to DES. The work of volunteers from coast to coast appear here.

We of DES ACTION have chosen to call our National Newsletter the DES ACTION VOICE because we hope it will represent just that—the *voice* to and for the DES exposed and those concerned about them, and the *action* to make the voice heard in solving problems arising directly or indirectly from DES exposure.

To achieve our goal, we have established a format of regular features that we would like to introduce here. In each issue, ". . . from the National Board" will report the plans and accomplishments of DES ACTION, National. "DES ACTION Groups in Action" is an update of the current activities of the local DES ACTION groups who focus on service to the people in their communities. We anticipate that reading about sister groups will inspire each of our groups to greater achievement. "DES and Government" will highlight state and federal DES related legislation, Food and Drug Administration and other Government activities, and special reports such as the feature on the DES Task Force appearing in this issue. In "DES and the Science Forefront", you will read about the latest research news. The focus will range from the current report on a symposium, to book reviews, and summaries and explanations of pertinent scientific and medical journal research reports.

We hope that the topics discussed in "Be An Enlightened Medical Consumer" will enable you to do just that. Information on the colposcope appears in this edition. In the future, we plan to address topics such as access to medical records, improving doctor-patient communications, contraception and any other subjects that you may request. Articles contributed by health care professionals, as the informative piece on DES sons, will be run as "Special Features". Finally, "DES and DAT" is the place for short news items and announcements.

We want to solicit your suggestions and opinions. Creative works such as poems and cartoons as well as "Letters to the Editor" are always welcome.

. . . from the National Board

History

DES ACTION, National officially began in May, 1978, when representatives for local DES groups in Boston, New York, Philadelphia, Washington, DC, San Francisco and Portland (Oregon) met in Washington.

Prior to this meeting, many of us had been working locally to educate ourselves about DES for some time, and in 1977 people from New York, New Jersey, Boston, Philadelphia, Springfield (Ill.), Connecticut, and San Francisco had met in New York City to discuss the feasibility of a national group. Given the scope to the problem, it was a logical solution, and we spent the next year working out the logistics of "DES ACTION, National."

At the New York meeting we discovered that we had all been working independently; in many cases unaware of each other's existence, trying to bring the DES story to the attention of the public and medical profession. We discovered that many of us were DES mothers or daughters, but that in spite of our first-hand experience with this drug, we knew little about it, or the problems it caused. Only through a large-scale effort, bringing thousands of women together from all over the country, could we exert sufficient pressure to assure that current and accurate information about diethylstilbestrol would be available to those who needed it.

We set one primary goal: to identify all persons exposed to DES and see that appropriate referral and follow-up care is available to them. The goal was simple enough, but in the year following, we discovered that achieving this goal involves huge political and economic questions: stories of cover-ups, burned medical records, and of course, ethical and moral questions.

To work toward that goal, we set a series of objectives necessary for identification of all people exposed to DES. These objectives are:

- —— obtaining medical information about DES
- —— learning how to organize and educate others
- —— providing education to consumers and professionals about DES and about the care needed by DES-exposed children.
- —— making sure further research is done on the many issues involved
- —— pressuring for the financial costs incurred through DES exposure to be met.

We were not organized to carry out this ambitious plan collectively, but we felt pleased that we had made this first step. We agreed to use the name "DES ACTION" for all our groups, to show our mutual association and support.

During the rest of the year we kept in close touch with each other, and in the spring of 1978 submitted a proposal to the *Ms.* Foundation for funding of a second organizational meeting. *Ms.* granted the money, and in May 1978 we spent three days in Washington, DC talking about our work, sharing skills and ideas, and bringing each other up-to-date on new medical information.

Since the Washington meeting, DES ACTION, National has really taken off. We have had a great deal of publicity and media attention because of the Federal DES Task Force report and because of the DES bill passed in New York State last summer (articles on both of these appear elsewhere). Numerous articles have been written about DES ACTION, National, and we have appeared on TV and radio several times. A feature TV documentary on DES ACTION, National has been made and distributed to a number of stations throughout the country.

In November the national board members met again—this time at our new headquarters in New York, where a diligent staff of volunteers tries to keep pace with the task of running both the New York and the National activities. At this meeting, we organized a network through which we could efficiently approach our goal of reaching DES-exposed people. We set-up a committee to centralize the preparation of written materials like the newsletter, brochures containing the most currently available facts on DES and other new information aids. We plan to make these materials available to as many people as possible. Another committee is concentrating its efforts on writing to foundations and private individuals to help finance our activities.

We also discussed how important it is to reach more people and to promote and support local self-help DES ACTION groups throughout the country. Why? Because we feel that the strength of DES ACTION, National depends on strong local chapters which can serve the needs of their communities. DES ACTION, National is the vehicle through which all DES-exposed can unite and be heard in a loud harmonious voice. If there is no DES Action group in your community, contact us and we will do what we can to help you get started. Don't forget that for each of you who knows about us, there are probably at least 10 people near you who don't know they have been exposed to DES and may need our help!

Meet the Board

In this first issue, we would like to introduce you to some of the people who put some of the 'action' into DES ACTION, National. The board of directors is a group of representatives of the various local groups who give in both administrative and advisory capacities.

Fran Fishbane, President, is well known in New York for her leadership in the local DES ACTION group and for her efforts to achieve legislation on behalf of the DES exposed. She was a consultant to the DES Task Force, and is presently involved with the implementing of the New York bill. Nancy Adess, Vice President, and Pat Cody, Treasurer, are activists in the Coalition for the Medical Rights for Women in San Francisco, from which their DES ACTION group has grown. Ms. Cody, a DES mother, is also on the Ad Hoc Advisory Committee on DES for the California Department of Public Health. Martha Izzi, another DES mother and consultant to non-profit organizations, is Secretary and one of the founders of the DES Action Project in the Boston area. Kathe Balter, a DES daughter, is an organizer in the Philadelphia group and works as a consultant in women's health care issues. Peg Beckwith, a DES mother, has coordinated DES ACTION in Oregon. Evelyn Karson, a DES daughter and Vice President of the Washington group, is a research biochemist at the National Institutes of Health. Mardi Marean is a nurse-colposcopist at Beth Israel Hospital in Boston. Libby Saks, a DES mother, is a former teacher now active in community affairs and DES ACTION N.Y. Dolores Wallgren, President of DES ACTION/Washington is also a DES mother.

Members of the medical advisory board are physicians who were selected because they are concerned about DES issues and recognized nationally for their experience in dealing with DES related problems.

Marluce Bibbo, M.D., Professor of Obstetrics and Gynecology and Pathology at the University of Chicago Lying-In Hospital, has been involved with the reevaluation and follow-up of persons exposed to DES in the study there in the early 1950's which suggested DES was not effective as a pregnancy maintenance drug. Louis Burke, M.D. is chief of the colposcopy clinic at the Beth Israel Hospital which is affiliated with the Harvard Medical School. Carmel J. Cohen, M.D. (Mt. Sinai School of Medicine), Burton A. Krumholz, M.D. (Long Island Jewish-Hillside Medical Center), Richard Levine, M.D. (Columbia Presbysterian Medical Center) and Norma Perez Veridiano, M.D. (Brookdale Medical Center) are gynecologists in the New York area.

Arthur T. Haney, M.D. (Department of OB/GYN, Duke University Medical Center), Robert N. Hoover, M.D. (Head, Environmental Epidemiology, National Institutes of Health), Leonard T. Kurland, M.D. (Professor and Chairman, Department of Medical Statistics Epidemiology, Mayo Clinic) and Howard Ulfelder, M.D. (Professor of Gynecology, Massachusetts General Hospital) are researchers who served on the DES Task Force. (see related article) Moreover, Dr. Kurland is coordinator for the DESAD project. Gerry Oliva, M.D., is Director of Planned Parenthood for San Francisco and Alameda counties, California and a member of the Ad Hoc Advisory Committee on DES for the California Department of Public Health. E. Douglas Whitehead, M.D. is a urologist at Beth Israel Hospital, N.Y. and researcher

into problems concerning DES sons. John Zerner, M.D. is a gynecologist from Maine who established an adenosis registry there and also has developed visual aids for teaching about DES.

As you can see, an extensive pool of talent is being directed toward dealing with the varied aspects of DES related problems. Each of these individuals has volunteered his or her time to work toward the DES ACTION goals on your behalf.

DES ACTION Groups In Action

Don't Mourn, Organize!!!

Local chapters of DES ACTION are continuing to do the necessary day to day work of identifying and getting help for the DES-exposed population of this country—and even in a few other countries. It is primarily through our collective efforts that DES has become a public issue, and that the federal and state governments have started to respond to our needs.

We still have a long way to go, though. The following reports represent efforts of over worked and underpaid DES activists. We all deserve a pat on the back!

BOSTON: Boston has organized a successful media campaign, including radio and newspaper spots and a new TV program. In addition, they are decentralizing their group so as to reach people in the Boston suburbs. Phone counselors are being trained to provide information, support, and referral to their local areas. The governor's commission on the status of women has filed a bill on behalf of DES exposed people.

SAN FRANCISCO: The California DES ACTION, funded by the National Cancer Institute has designed a model outreach program, providing training for nurses and surveying physicians about further DES training. They have also designed an excellent information flyer which will be made available to other groups.

OREGON: The Oregon group is just in the beginning stages of formation and has begun to attract media attention. This group is experiencing the same frustration that we have all felt in developing local chapters. We wish our Oregon friends the best of luck in their new efforts.

NEW YORK: DES ACTION/NY is working with the state in implementing the newly passed DES legislation. In addition, New York is continuing to do media spots, and educational seminars. For fund raising, NY has sent out 4000 appeal letters and is pleased with the response rate. Volunteers are now working out of their beautiful, donated offices at Long Island Jewish Hospital, which also serve as our national headquarters.

WASHINGTON, DC: Washington has successfully sponsored a series of educational forums, which have highlighted guest speakers such as Drs. Diane Fink and Bruce Stadel. Sidney Wolfe is scheduled to speak in January. Also, Washington has been making the most of the media, including a TV program, radio interview and newspaper announcements. They now have an office in a local school. With the aid of a grant from the IBM Corp. the group is working to develop audiovisual aids to be included in educational programs for the public.

SOUTHERN CALIFORNIA: This newly-formed group is gaining media attention through appearances on the Health segment of their local T.V. news. Discussion groups for the husbands of DES daughters are being planned. Working with the San Francisco group, Southern California hopes to influence legislation for the DES exposed.

PHILADELPHIA: The Philadelphia group is attempting to step up their activity despite their frustration over a lack of steady volunteers. A community educational was sponsored in November, and the meeting was widely publicized by a radio interview and Public Service Announcements. Plans for more educationals in different parts of the city and suburbs, newspaper articles, and in-service training at women's clinics are all in the works.

New groups are forming in other parts of the country and news from them will appear in future editions of this newsletter.

DES and Government

DES Task Force

The involvement of the Department of Health, Education, and Welfare in evaluating the effects of diethylstilbestrol (DES) is not new. In 1974, the National Cancer Institute Division of Cancer Control and Rehabilitation began funding the DESAD project—a cooperative study of adenosis and genital tract changes in DES daughters and the possible relationship of these changes to cancer. Research centers at Baylor College of Medicine, Massachusetts General Hospital, University of Southern California, and the Mayo Clinic are conducting the research. A followup study on the mothers who participated in a clinical trial of DES in the early 1950's at the University of Chicago has also been supported by the National Institute of Child Health and Human Development (NICHD). Indeed, it was an interim report from this group that suggested there might be an increased risk of breast cancer for DES mothers and that the cancers occur at a younger age. Consequently, Dr. Sidney Wolfe of the Nader Health Research Group and others directed letters to HEW Secretary Califano. Fran Fishbane of DES ACTION met with HEW officials urging that action be taken to investigate DES related health problems.

Ultimately, the Task Force was commissioned by Secretary Califano and charged "to review all aspects of DES use in humans and develop recommendations regarding research gaps and health issues and to advise on a possible association of breast cancer in DES mothers, the use of DES as a postcoital contraceptive, reproductive tract changes in sons, cancer and tissue changes in DES daughters and other health effects of DES".

On March 3, 1978, the Task Force convened with Dr. Diane Fink, director of DCCR as chair and Dr. Mary Ann Sestilli, assistant program director, as executive secretary. Subsequent day-long meetings were held monthly and on September 21, the final report was sent to Dr. Julius Richmond, Surgeon General and Assistant to Secretary Califano.

Who were some of the other prominent figures in the Task Force discussions? Dr. Wolfe, of course continued his vigilance. Drs. Heinz Berendes, Philip Corfman, Robert Hoover, and Bruce Stadel are epidemiologists from the National Cancer Institute and the NICHD who have been active researchers in the area of estrogens. Drs. Leonard Kurland and Kenneth Noller (Mayo Clinic), Howard Ulfelder and Ann Barnes (Massachusetts General Hospital), Raymond Kaufman (Baylor College of Medicine), and Duane Townsend (University of Southern California) work on the DESAD project. Dr. Arthur Herbst was one of the authors of the earliest reports linking DES to a rare type of adenocarcinoma in daughters. Other gynecologists, psychologists, toxicologists, government staff, and DES exposed persons, including several DES ACTION members, participated in the presentations and discussions of the Task Force. Researchers were invited to present their most current findings and answer questions in person so that as much of the new information about DES and the effects of its use could be evaluted.

What were the consequences of the report? A physicians advisory was sent to 400,000 doctors on October 4, 1978, highlighting the major conclusions and recommendations of the committees. Notification of exposed persons, where possible, and full disclosure upon request were advocated. Routine screening rather than active theraputic intervention (such as surgery or radiotherapy) for adenosis was advised and guidelines for examinations were described. Women under 50 were cautioned against mammography in the absence of symptoms or a personal or family history of breast cancer, but were encouraged to practice monthly self-examination and have annual pelvic and breast examinations by their doctor. Also, the Task Force concluded that the use of DES and other estrogens for contraceptive and/or post menopausal therapy should be avoided where possible by the DES exposed. Moreover, the use of DES as a postcoital contraceptive (morning after pill) was discouraged, particularly for the DES exposed. Sons were advised to undergo physical

examination for undescended or hypoplastic (small) testes because these conditions, even in the absence of DES exposure, require corrective therapy and suggest an increased risk for testicular cancer. No definitive information on the fertility implications of any of the genital tract changes in the offspring was available. Each of these summary topics is detailed further in the actual Task Force report which contains appendices describing the scientific studies reviewed for each of the groups—mothers, daughters, and sons. (Editor's note: you can obtain a free copy of the Task Force report by writing to: National Institute of Health, Office of Cancer Communication, Bldg. 32, Room 10A29, Bethesda, Md. 20014.)

What are the future implications of the Task Force work? It was recognized that various questions about DES cannot be answered because reliable information is not available. Accordingly, it was recommended that appropriate studies be established or continued to follow the breast and reproductive system changes and/or cancers as the exposed persons age; to obtain more information about possible fertility problems in sons and daughters; to evaluate the individual and family psychosocial problems related to DES exposure; and to investigate possible long term effects of exposure by using animal research studies. Furthermore, it was suggested that the Task Force be reconvened to evaluate new information when it becomes available.

Meanwhile an active professional education campaign is planned for health care providers such as nurses, social workers, psychologists, and physicians; in particular family practitioners, internists, pediatricians, gynecologists, surgeons, pathologists, obstetricians, psychiatrists, and urologists. Short course and educational materials will be made available through professional societies, health departments, and other centers and organizations as can be arranged. In addition, public information campaigns will be expanded. We of DES ACTION plan to cooperate and work with these Department of Health, Education, and Welfare programs in whatever ways possible to help achieve our common goals.

DES and the F.D.A.

On September 21, 1978, Judge Daniel J. Davidson ordered that the Food and Drug Administration withdraw its approval of diethylstilbestrol (DES) for use in animal feed and implants as a growth stimulant. This decision hopefully marked the "beginning of the end" of a lengthy battle in which the public, the scientific community, the drug industry and the Federal government have been at odds over the issue of whether DES in beef or poultry is carcinogenic (cancer-causing) to the human consumer. The following outline of the history of FDA's actions with regard to DES is presented to highlight the importance of Judge Davidson's judgment.

In 1941, the FDA first approved DES for use in human medicine; and in 1947, on the basis of the available scientific data, for use in animal feed and as pellet implants. But in 1958, further tests showed that DES caused cancer in laboratory animals, and because of a new Food Additives Amendment, the FDA would not give *new* approvals to drug manufacturers for production of DES (old approvals were still in force, however). How much residue remained in meat after DES was ingested by animals was still unclear, and in 1959, scientists had developed tests to detect relatively low levels of DES residue. Using these tests, it was found that the amount left in poultry was too high and the FDA withdrew approval of DES in poultry. It was assumed that the lack of DES residue detected in beef and sheep meant no potential harm to humans—but it was not known how sensitive the test was, and there may have been residues present. Closer and more sensitive monitoring beginning in 1971 showed a very low level of residue in only 1% of all samples taken (the rest showed none)—and it was felt that waiting seven days after the last use of DES to slaughter would reduce any residue to the undetectable range. Delaying slaughter, and radioactive tracer studies to test for minute residues, were begun. But the public, by 1972, was not about to let the DES issue rest, and because the radioactive tracers showed higher and higher levels of DES in meat, the FDA withdrew its approval for DES use in feed and implants by April 1973. They did not recall DES or any meat, however, and since their withdrawals had come without public hearings, the drug industry went to court and had the decisions reversed in January 1974. Twice, once in 1972 and again in September 1975, the U.S. Senate passed bills outlawing DES, but the House of Representatives never took action. This is where the issue stood until September 21st, 1978.

The "ultimate findings and order" outlined in Judge Davidson's recent report are as follows:

(1) "DES is a carcinogen and there is no known 'no-effect' level for its [cancer-causing] properties.

(2) "DES has adverse biological effects that call its safety into question . . . and safe tolerance levels have not been established . . .

(3) "The existence of residues in [meat] resulting from the use of DES has been sufficiently established to call its safety into question . . .

(4) ". . . these residues are likely to occur when the approved conditions of use are followed.

(5) "The . . . method [now used for detecting DES residues] . . . is not adequate . . . because it is incapable of detecting and identifying all residues . . .

(6) "[There is insufficient evidence] that other detection methods are adequate . . . [or] sufficiently sensitive to detect such residues at low enough levels to be considered safe for human consumption.

(7) "DES has not been shown to be safe under the previously approved conditions of use . . .

(8) "The public health, environmental and economic benefits, if any, from the continued use of DES as an animal growth [promoter] have not been shown to outweigh the potential health risks resulting from the use of DES . . .

(9) "The withdrawal from the market of DES for use [in animals] will not significantly affect the quality of the human environment.

(10) "*It is ordered* that approval . . . for DES . . . be . . . withdrawn . . . ."

Judge Davidson's decree is the result of a hearing, and constitutes only an "administrative judgment", showing FDA's informed opinions. The industries have appealed the ruling. Exclusive of a lengthy appendix, the exceptions filed by various sources are more than 200 pages long. The review process could be a lengthy process and possibly take several more years. Can they argue successfully against such a well-researched administrative judgment from the FDA? The decision now belongs to the FDA commissioner, Donald Kennedy and no real time has been set for his determination.

DES Legislation in Maine

As we went to press, notification from a representative from Maine, Merle Nelson, was received by the DES Action/N.Y. office. Maine will be introducing legislation similar to the N.Y. law. Contact your legislators to urge for DES laws throughout the country. Let's hope that as Maine goes, so goes the nation!

DES and N.Y. Legislation

It is estimated that at least one hundred thousand persons in New York State were exposed prenatally to DES. The vast majority are unaware of their exposure and have not been adequately screened.

By unanimous votes in both the State Senate and the Assembly, the N.Y. Legislature passed the first state bill that would provide for the effective identification, screening, diagnosis, care and treatment of persons who have taken DES, or who have been exposed to DES prenatally. DES ACTION New York, guided by Fran Fishbane, worked persistently to insure its passage.

The bill calls for the development of a public information campaign and the establishment of screening centers throughout N.Y. A voluntary registry of DES exposed persons would be maintained for the purpose of follow-up care and treatment of long-term problems associated with DES exposure. It provides professional education programs for physicians, physician's assistants and nurses. In addition, the bill would prohibit insurance companies from denying health or accident policies for DES related reasons.

The Scientific Advisory Committee on DES will determine the regional screening centers. Those facilities chosen will utilize procedures recommended by the Task Force. This Newsletter will keep you informed of the progress by N.Y. in establishing an effective DES program.

Special Feature

Intrauterine DES Exposure and Urogenital Disorders In The Male

E. Douglas Whitehead, M.D.

From the 1940's to 1971 it is estimated that approximately one million American males were potentially affected by intrauterine exposure to diethylstilbestrol (DES), a synthetic estrogen, that had been prescribed to prevent spontaneous abortions and, more recently, as a post-coital contraceptive.

Only recently have certain established associations been noted among DES exposed males. In a "Physician Advisory", dated October 4, 1978, the Department of HEW outlined a DES Task Force review of clinical studies and presented recommendations for managing patients exposed to DES *in utero*. With respect to such males it was noted that these studies indicated established associations of an increased frequency of: 1) a history of cryptorchidism, 2) hypoplastic testes, 3) epididymal cysts, and 4) semen abnormalities, such as low sperm counts, decreased motility and abnormal morphology. It was concluded that, at the present time, there was no definitive information on the fertility implications of the semen abnormalities, and it was noted that additional studies were needed to evaluate the possibility of an increased risk of carcinoma of the testes in DES exposed males.

The DES task Force made the following observations and recommendations regarding males exposed to DES *in utero:* 1) physical examination should be performed to detect abnormalities associated with DES exposure, such as undescended or hypoplastic testes, 2) such abnormalities should be followed medically or corrective measures employed (it was stressed that even without DES exposure undescended or hypoplastic testes were predisposed to testicular malignancy) and 3) testicular self-examination, which is recommended by some physicians and consumer groups, is safe but unproved as a satisfactory screening method.

The male concerned with DES related illness is often extremely fearful and anxious by the time he seeks medical counsel. He is frequently aware of the risks of vaginal and cervical carcinoma (clear-cell adenocarcinoma) in females whose mothers took DES in their pregnancy. This awareness, together with the recent heightened publicity and lay concern of possible environmental carcinogens, adds further to their anxiety. However, unlike studies linking DES exposure and vaginal and cervical carcinoma in the female, to date, there does not appear to be any published report of associated carcinomatous change in the DES exposed male.

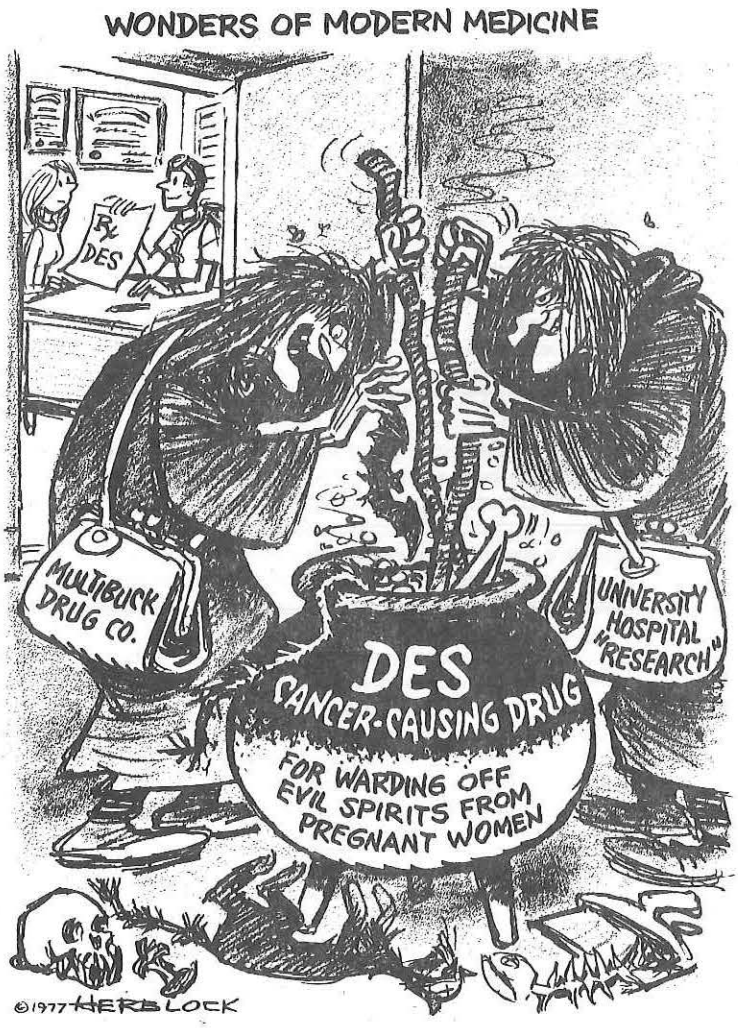
Recently, attempts have been made to establish registries, regional centers and a national cooperative study to: 1) identify patients exposed to DES, 2) establish screening programs for patients exposed to DES, 3) develop evaluatory and follow-up techniques for patients exposed to DES, 4) evaluate treatment modalities used for DES associated problems, and 5) maintain records of patients exposed to DES.

At the present time, until further data has been gathered, the recommendations made by the HEW Task Force are being followed. Specifically, male patients with a history of DES exposure *in utero* are being examined, preferably by a urologist, to find out if there are any congenital abnormalities as noted in the "Physician's Advisory". If undescended or hypoplastic testes are noted, the patients are counseled regarding the increased incidence of testicular malignancy and the need for medical or surgical care. Currently, all male patients with a history of DES exposure are advised to perform self-examination of the testes in the shower or bathtub approximately every month, in view of the common origin of some of the male reproductive organs with that of the female reproductive organs and the possible concern for the subsequent development of testicular malignancy. Furthermore, the availability of radioimmune assay of beta sub-unit human chorionic gonadotrophin and radioimmune assay of alpha-fetoprotein, and their role as biologic markers in certain types of testicular malignancies are discussed and possibly considered in order to relieve the patient's anxiety or apprehension, even after a negative physical examination of the genitalia. Additionally, male patients with a history of DES exposure are advised to consider having a semen analysis at the time of examination, or in the future if the patient is too young, to detect significantly impaired semen parameters in order to counsel the patient of the possible significance of such findings in terms of later fertility or infertility, which is, to a large extent, unknown at the present time. If an initial abnormal semen analysis is found, at least one repeat semen analysis, at monthly intervals, is recommended. Finally, the patient is advised to periodically call the physician on the phone to inquire of any additional new developments relating to the health effects of DES.

It is hoped that through, 1) increased physician awareness of male DES associated abnormalities, 2) registries of DES exposed males, 3) regional centers, and 4) a well-conceived national study, many of the unresolved questions regarding DES exposed males and possible causal relationships of DES and abnormalities of the male reproductive system, including possible risks of malignancy will be resolved.

HERBLOCK'S CARTOON

Dec. 2, 1977



Will you receive the second issue of DES Action Voice? If you are not a subscriber or supporter of a local group—fill out the enclosed coupon on page 7.

DES and the Science Forefront

Report From Houston

"Medical Innovation and Public Policy: The Case of DES" was the title of a symposium sponsored by the American Association for the Advancement of Science on January 6. This program was part of their annual three day meeting held in Houston, Texas The purpose of this session was to raise and discuss questions about the costs: risks (financial and human) of medical innovation to society and the implications for public policy. The unexpected consequences of DES utilization have demonstrated that scientific and technical innovation of experimentation may have hidden social costs. Although the specific problems may not be predictable, they must be anticipated in overall planning.

Speakers representing a variety of professional disciplines were featured. The session opened with a talk by Dr. Kenneth Noller, Deputy Director for the DESAD project, Mayo Clinic, who reviewed the history of DES related problems in daughters and reported the latest project findings. Dr. Marion Finkel, of the Bureau of Drugs of the Food and Drug Administration recounted the history of DES for human usage from its first approval in 1941, through its ban for use in pregnancy maintenance in the early 1970's, to its current withdrawal for use in lactation suppression and the reconsideration of its use as a postcoital contraceptive. Raphael More, representing the Chemical and Atomic Workers Union discussed the consequences of occupational exposure to the drug. He cited the case of Dawes Laboratories in Chicago, in which the manufacture of DES was halted. The workers were assigned to other jobs in the company, and affected individuals (including males who developed enlarged breasts and/or sterility from the exposure to DES) received appropriate medical care and follow-up. Fran Fishbane, president of DES ACTION/National spoke of both the impact and the limits of the work of DES ACTION and other public interest groups in helping the DES exposed and emphasized the importance of legislation to protect the rights of and help finance the added medical expenses. Lane Bauer, an attorney representing drug companies focused his remarks on the case against Eli Lilly in Michigan and the difficulty of identifying the defendant in a case because over 90 companies manufactured the unpatented drug. Fay Saber, assistant professor of law at Wright State University Medical School in Dayton who also holds a masters degree in Public Health from Harvard Medical school, further examined the topic of legal responsibility for DES related damages. She delineated some of the legal problems facing DES plaintiffs in litigation against either the drug manufacturers or FDA and the Federal Government. She suggested that certain medicolegal issues may best be dealt with through legislative actions. (An article on this subject written by Ms. Saber will appear in the next edition of this newsletter). Drs. Betsy Carleton and Jonathon King of the Massachusetts Institute of Technology addressed the issue of research funding policy. Specifically, funding to study the mechanics by which DES affects cells is inadequate. Moreover, enlightened policy perspective suggests that the presidential advisory board for health issues should include more representatives concerned with consumer protection to counterbalance the "big business" input.

A more detailed account of the proceedings of this program can be found in *Science* Magazine.

Be an Enlightened Medical Consumer

The Colposcope

(Editor's note: there is controversy even amongst physicians as as to the role of colposcopy in examination of the DES exposed. We hope this article will enlighten you on this issue.)

The colposcope is an instrument that magnifies like a microscope. When used by a trained and skilled practitioner, it can aid in recognizing changes in the cells of the vagina and cervix. Because no part of the machine touches the body, it cannot harm the tissues. Why then, is there such controversy about its use? How can the patient make an educated decision about how necessary colposcopy is for her or her daughter?

There is little doubt that the colposcope is a valuable diagnostic tool when used by an expert. As one well known colposcopist has said, "Take two people looking up at the stars in the night. One is looking through a telescope. Who do you think sees the stars with more clarity?" A problem may arise in the interpretation of what is seen. Clearly the astronomer, who is familiar with the patterns in the sky, can recognize a new object and distinguish a planet from a star more readily than an ordinary person who seldom looks at the sky. So it is with colposcopy. Some skilled colposcopists say that in order to broaden and maintain their knowledge, they must see many DES patients and many unskilled practitioners see too few DES exposed to become familiar with and interpret some of the subtle colposcopic findings. For example, the appearance of a vascular (blood vessel) pattern in non-DES exposed women may signify abnormality, whereas it is a common finding in the DES exposed. Aggressive treatment may not be appropriate. Indeed, surgical procedures may be unnecessary and possibly dangerous. The inexperienced colposcopist, however, may not be able to distinguish such findings from those requiring prompt treatment. Thus, it is often wise to seek a second opinion when the conclusion of abnormal findings suggests treatment.

Colposcopy may also be expensive. The cost of the instrument and training may contribute to this factor, especially if the doctor sees few patients requiring this specialty. Unfortunately, there are stories of physicians (some of whom dispensed DES in the past) who now charge more than $100 for each examination. Moreover insurance coverage for a colposcopic exam is not uniform for al companies and policies. Consumers beware!

So far, the discussion has dealt with situations in which colposcopy is a readily available choice. For those residing in a rural setting without easy access to medical facilities which care for many DES exposed, or those who do not choose colposcopy, there is an alternative. An examination by someone thoroughly familiar with DES related changes is essential, and it should include the following procedures which are used with colposcopy, when it is done. First, a physical examination (palpation) of the entire vagina and cervix is done to rule out any nodules which may signify a tumor or abnormal growth. Next, Pap smear, including a sample of the endocervix is also essential. Iodine staining is a simple technique by which many vaginal epithelial changes (cellular changes such as adenosis) can be visualized. If any of these methods indicate abnormality, a biopsy (small sample of tissue removed with a forceps for examination under a microscope by a pathologist) should be taken. Abnormal biopsy reports should be confirmed by a pathologist who is familiar with DES related changes.

Thus, physical examination, cytology and histology (Pap smears and biopsies), and colposcopy do not compete. Rather, each enhances the reliability of diagnosis when performed by trained individuals. Because of inaccessibility of colposcopy (geographic or economic considerations) the age of the patient (the incidence of DES related cancer decreases dramatically after age 22), or other factors, some DES exposed women may choose to have colposcopy only during their initial visit or occasionally at return visits. Others who live in or travel to large metropolitan areas

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We hope you have enjoyed reading this first edition of DES ACTION VOICE. To receive future issues, you must be a current subscriber or supporter of your local DES ACTION group. If you are not sure if a group exists in your area, your subscription and information requests will be handled by DES ACTION National directly or forwarded to the appropriate local group. Please use the enclosed coupon to be sure you don't miss a single informative edition. The yearly subscription rate (4 issues) is $15. Subscribe now and start 1979 off right!

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DES Action/Northern California
4079A-24th Street
San Francisco, Ca. 94114

may find it reassuring that a skilled colposcopist is watching carefully. The choice is yours. As informed patients, we can seek more than one opinion and consider many factors when making decisions about our health care.

'DES AND DAT'

The National Women's Health Network announces the publication of a series of health resource guides on the following subjects: DES, Breast Cancer, Menopause, Hysterectomy, Abortion, Birth Control, Maternal Health, Sterilization, and Self-Help. If interested, send a check for $3, payable to the National Women's Health Network, 2025 I Street, N.W., Suite 105, Washington, D.C.

For help in obtaining your medical records—request *"Getting Yours*—How to get your medical records in 50 states" from Health Research Group, 2000 P St. Suite 700, Washington, D.C. 20036.

New address for the American Society for Colposcopy:

ASCCP, Charles B. Slack, Inc.
6900 Grove Road
Thorofare, N.J. 08086
Phone—609-848-1000

Direct your concerns regarding the delays of the Task Force to: Dr. Arthur Upton, Director National Cancer Institute, Building 31, Bethesda, Maryland 20014.

Many thanks to our great volunteers. Without the kindness and help of these wonderful people, we could not grow as we have.

Letters To The Editor

Dear Friends at DES ACTION,

I want to thank you for your presence, caring, but most of all, your knowledge. Without the information that I received from DES ACTION, I would have remained a passive, uninformed patient.

I want all those exposed to DES to be able to make intelligent choices. Therefore, when I read Family Doctor, 2/79 in *Good Housekeeping* and found it minimized the DES situation and neglected to stress the importance of a DES trained physician and complete DES screening, I was appalled.

I urge all those committed to the proper care of DES exposed to write to Good Housekeeping. Request that they present the facts, not continue to lull into complacency and INACTION those thousands not receiving proper care.

Sincerely,
A DES Daughter
(name withheld upon request)

Dear Sisters,

Congratulations on the first issue of *DES ACTION National Voice*, and on the formation of DES ACTION groups throughout the country. Hopefully, in 1979 we'll see groups in all 50 states!

So much has happened since 1972, when the first publicized report of the DES cancer tragedies appeared in the feminist press (herself newspaper). It was only 4 years ago that the collaborative efforts of Nancy Belden, Sherry Leibowitz, Doris Haire and I brought DES to the attention of the Congress.

Senator Kennedy's bill to restrict DES as a contraceptive never made it through the House. The use of the "morning-after" pill is still used for rape victims and Congress never appropriated funds to assist DES families.

Women's work is never done! We look to the DES ACTION National Newsletter to provide us with the information and insights necessary for effective community organizing. Again, congratulations! And especially to Fran Fishbane whose pioneering work led to the nation's first DES law (New York State).

In Sisterhood,
Belita Cowan
National Women's Health Network

Express your viewpoint! Address letters to:
Editor, DES ACTION VOICE, LIJHMC
New Hyde Park, N.Y. 11040
Due to space limitations we will occasionally condense letters.

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