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EXPOSURE TO DIETHYLSTILBESTROL

A Report by
The Commissioner of Human Services
To
The 110th Maine Legislature

February 1, 1981

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THE MAINE DES PROGRAM

Diethylstilbestrol (DES) is a synthetic hormone used widely from the late 1940s to 1971. It was administered by physicians to pregnant women threatened with miscarriage. In recent years, however, medical science has discovered that daughters born to women who took DES have a greater than usual risk of developing a rare type of vaginal cancer, clear cell adenocarcinoma. Vaginal adenosis, a benign condition, has also been frequently discovered in DES exposed daughters.

In recognition of the seriousness of DES-related problems, L.D. 635, An Act Concerning Persons Exposed to Diethylstilbestrol (DES) was passed by the Maine Legislature in 1979 and signed into law by Governor Brennan in June of that year. This legislation directed the Maine Department of Human Services: to establish, promote and maintain a public informational campaign on DES; to actively seek providers of health care to participate in regional programs to provide public information and screening for DES exposed persons; to establish and maintain a voluntary registry of women who took DES during pregnancy and their exposed offspring for the purpose of follow-up care and treatment of long term problems associated with DES exposure. The law also assures that no one will be denied accident or health insurance solely because the mother of the insured has been discovered to have taken DES.

In response to this legislation, the Bureau of Health within the Department of Human Services has initiated a DES Program with

three major components: (1) Health Professional Education (2) An Information and Referral Network for DES Exposed Individuals and (3) Public Education and Awareness. One of the first steps taken by this program was the establishment of a DES Medical Advisory Committee. John Zerner, M.D., FACOG, of Portland, a nationally recognized expert on the problems of DES, has been selected to chair this thirteen member group of health professionals from throughout the State. (Membership list attached) The Committee serves as a consultative resource to the program in the areas of public and professional education and assists in the identification of appropriate referral sources for DES exposed individuals. The Department is also working in partnership with the American Cancer Society, Maine Division, to implement a number of aspects of the Program. A detailed program plan including specific objectives and an evaluation component has been written and reviewed by the Advisory Committee. (available on request)

Educational programs for various groups of health professionals have been held in a number of locations throughout the State. A great deal of local education directed at obstetricians and gynecologists through their professional association has been conducted by John Zerner, M.D. Articles by Dr. Zerner have also appeared in the Journal of the Maine Medical Association. Other programs on the medical counselling, and legal aspects of DES have been presented to nurses, physician assistants, rural health center personnel, family planning nurse practitioners, counsellors and educators. At the initial meeting of the DES Medical Advisory Committee an educational

session was held for members as well as agency representatives from the American Cancer Society, Maine Division, and the Department of Human Services.

Professional journal articles related to the issue of DES have been collected and made available to interested health professionals. The program is awaiting release of a new publication by the National Cancer Institute specifically for physicians. Once this material is received, a special DES folder containing this publication as well as other appropriate information for Maine physicians will be distributed. The Department's Communicable Disease Report which is sent to all physicians, health officers and school nurses also carried an article describing the DES Program in its November issue. In conjunction with the Professional Education Committee of the American Cancer Society, Maine Division, additional programs will be planned for the current year.

In order to establish a voluntary registry of persons exposed to DES, the Division of Health Education within the Department has entered into a cooperative arrangement with the Sidney Farber Cancer Institute in Boston. Through their Maine Cancer Information Service, people in Maine are now able to call a toll-free number (1-800-225-7034) where in addition to receiving basic information about DES, they are asked if they wish to be placed on a mailing list to receive word of new DES findings and developments. This service began in December. All follow-up communications sent by the Cancer Information Service will be reviewed and endorsed by the DES Medical Advisory Committee. Arrangements have also been made by the DES Program to provide answers to legal questions regarding DES exposure through

the voluntary cooperation of a number of Maine attorneys.

Increasing the public's awareness and understanding of the problems associated with DES exposure are key areas of program emphasis. Prior to the development of a specific plan of action, a statewide survey was conducted last June in cooperation with the University of Maine's Social Science Institute. The purpose of this activity was to gather information for program planning and evaluation. (Appendix I) Nearly 30% of the women questioned had not heard of DES. Even among those women who had heard of DES, only about 20% of them had ever asked any one if they were exposed. Nearly one-fifth did not know that the daughters of women who took DES during pregnancy could develop health problems as a result. Women in York and Cumberland counties were far more likely to have asked someone if they had been exposed to DES, than women in the Penobscot, Piscataquis, Hancock and Washington group of counties. Significant differences were also found between the educational level of women and whether or not they had heard of DES. Family income level was also associated with whether or not the women knew that daughters could develop problems from prenatal DES exposure.

Efforts to launch a Statewide DES Awareness Campaign to address the issues documented by the survey results have begun. As an initial step, the week of March 23rd has been designated as the first annual Maine DES Awareness Week. This strategy will provide maximum media attention to the issue of DES and will enable the program to identify and promote those resources that have been

developed to assist the public with questions regarding DES. A student intern from the University of Maine at Farmington has been working with the program on this effort.

Educational materials from other states have been received and adapted for use in Maine. The State of New York has been especially helpful in providing assistance and consultation. They have allowed Maine to use their television and radio scripts that were developed, to duplicate their written material and have even given us permission to use their program theme, "DES the Wonder Drug Women Should Wonder About". Through such vehicles as television and radio public service announcements and talk shows, news stories and articles, posters, brochures and payroll stuffers, Maine citizens will be informed of the issue of DES and urged to ask if they have taken or been exposed to the drug. Use of the toll-free DES information number will be promoted for those who want more information and who wish to be placed on the mailing list for future correspondence.

While a great deal of program emphasis will be placed upon the annual DES Awareness Week effort, public education activities will continue throughout the year. At least two more public service announcements will be produced to supplement the one spot which is already being shown. A slide/tape program has been adapted for use in Maine and will continue to be loaned to groups who wish to know more about the problem. A display has been constructed by Dr. Zerner and is available for the program to use

at both public and professional gatherings. Thousands of brochures have been sent to us free of charge from the National Cancer Institute and we are awaiting a number of their new publications.

We are also in contact with the other state health departments in the country who have DES Programs. This informal network has been useful for sharing ideas and approaches to both professional and public education. By communicating with states in which the DES Program has been staffed and in operation for some time, we have avoided wasting time and money duplicating activities that have already been done elsewhere.

In the short period of time since the DES Program began, a great deal has been accomplished. Through the assistance of the Sidney Farber Cancer Institute in Boston, information and referral services are now available for Maine citizens who have been exposed to DES. With the help of the American Cancer Society, Maine Division, professional education and public information efforts have been initiated. Three Maine attorneys, Robert E. Hirshon, Thomas Allen and John Kelly, have agreed, at no charge, to answer legal questions from callers who are referred by the Maine Cancer Information Service. The Medical Advisory Committee has been a valuable source of assistance and advice. Dr. Zerner, the Committee Chairman, has given many hours of his time to this program. The Maine DES Program is fortunate to have an advisory committee chairman who, in addition to being dedicated to the program, is also

one of the most knowledgeable physicians in the country on the problem of DES. Through the cooperative efforts of both the public and private sectors, the Maine DES Program has been successfully established and is in productive operation.

June 1980 Omnibus Telephone Survey
Social Science Research Institute
University of Maine at Orono

DES

From the June 1980, Omnibus Telephone Survey, a series of eight questions concerning the knowledge level of the drug diethylstilbestrol (DES) were asked of females who comprised fifty-five percent (55%) of the sample survey.

Nearly three-fourths (75%) of the women sampled had heard of DES. As might be expected, of the women who had heard of the drug, approximately seventy percent (70%) had learned of it through the media, mainly through television, newspaper or radio. Slightly more than forty percent (40%) of the women interviewed remembered seeing or hearing a television or radio announcement on diethylstilbestrol within the past six months. We suspect that a great many of these people learned of DES through the nationally broadcast "Lou Grant Show" which featured the topic in one episode. Thirteen percent of the women who knew of the drug had heard of it from either a physician or a health agency.

Eighty percent of the women sampled had never asked anyone if they had been previously exposed to DES. Most of the women who had asked someone about their exposure to DES, had asked their parents. Very few women had asked their physician or anyone else if they had ever been exposed to DES.

While most women had a limited amount of knowledge concerning the effects of DES, eighty-two percent (82%) felt that if a woman took DES during pregnancy that a female child could encounter medical problems as a result of the exposure. Almost half of the respondents did not know what the consequences were for a male child.

The need for a public awareness campaign was demonstrated with an overwhelming majority, ninety percent (90%), of women saying that they are not aware of a DES information service in the State of Maine.

JUNE 1980 OMNIBUS TELEPHONE SURVEY
 SOCIAL SCIENCE RESEARCH INSTITUTE
 UNIVERSITY OF MAINE AT ORONO

DES

QUESTIONS	RESPONSE	%	#
. Have you ever heard of the drug DES (diethylstilbestrol), a hormone that was used to prevent miscarriages and other problems in pregnancy?	NO	27.5%	74
	YES	72.5%	195
. How did you hear about DES?	Television	69.2%	135
	Newspaper	61.0%	119
	Radio	18.5%	35
	Relative/friend	17.4%	34
	Physician	8.2%	16
	Health agency	4.6%	9
	Other	17.8%	39
. If a woman took DES during pregnancy with a female child, could her daughter possibly develop any medical problems as a result?	YES	82.5%	160
	NO	1.1%	2
	Don't know	16.4%	32
. If a woman took DES during pregnancy with a male child, could her son possibly develop medical problems as a result?	YES	22.2%	43
	NO	28.9%	56
	Don't know	48.9%	95
. Have you ever asked anyone if you were exposed to DES?	YES	20.6%	40
	NO	79.4%	154
. Who did you ask?	Parent	82.9%	34
	Physician	12.2%	5
	Other	4.9%	2
. Are you aware of a DES information service in Maine	YES	8.9%	17
	NO	90.6%	174
	Don't know	.5%	1

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