

**MEETING REPORT**

**for**

**Contract Number 200-98-0102**

**DES NATIONAL EDUCATION CAMPAIGN FOR CONSUMERS AND HEALTH CARE  
PROVIDERS MEETING  
August 24, 1999**

**Atlanta, Georgia**

**to**

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# GOALS AND EXPECTATIONS

## THE NATIONAL EDUCATION CAMPAIGN ON DES SHOULD

### Goals for Consumers

- # Include and educate DES sons. They have been overlooked in past efforts.
- # Educate potentially exposed consumers to take charge of their own health care and help to educate providers (i.e., know and ask for proper health care<sup>1</sup> guidelines for DES exposed individuals). Consumer and Provider education should reinforce each other.
- # Reach neglected populations, including geographic regions of the country that have not had much DES education in the past.
- # Reach consumers through existing health resources and determine effective ways to reach consumers not actively looking for health information.
- # Collect baseline data on population numbers affected and the level of population knowledge of DES in order to measure outcomes and quantify objectives.

### Goals for Providers

- # Educate health care providers<sup>2</sup> about DES. The outcome is to not see blank stares, so that providers would be aware of DES as a current health issue (specifically, knowing about DES and the adverse health outcomes it causes) and take it seriously (not dismissing the current risk it poses to patients and changing their practices to reflect this awareness).
- # Bring the state-of-knowledge about DES up to year 2000 standards.
- # Link ongoing research to the efforts of the national education campaign (particularly for provider education).
- # Develop (or advocate for and publicize) an easy to remember, always there central informational resource for providers to receive the most up-to-date information about DES (e.g., a provider hotline). Locate the resource in an agency respected by physicians.
- # Continue for a long time because of the possibility of multi-generational effects and the need to disseminate the results of on-going research.
- # Collect baseline levels of knowledge, attitudes, and practices of health care providers regarding DES.

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<sup>1</sup> Health care does not only include medical care.

<sup>2</sup> Health care providers include *all* health care providers not only physicians (e.g., nurse practitioners, nurse midwives, etc.).

## Goal for the General Public

- # Encourage all Americans to regard DES as a cautionary tale which warns about the pharmaco-opportunistic culture we have created that regards drugs as quick solutions. We need to be more cautious about drug use and cannot stop research in 3-5 years and declare a drug safe.

## Goals for Partnership

- # Utilize both environmental and health networks to disseminate information about DES (utilizing current awareness of endocrine disruptors to boost efforts to educate about DES). [There is a fear that such an approach may dilute the message and confuse consumers as endocrine disruption is still controversial within the environmental community].

- # Collaborate with international DES groups to coordinate efforts in several sites

- # Coordinate with professional medical associations including specialty societies to disseminate DES messages in the most effective ways for those professions. Groups could include:

- American College of Obstetrics/Gynecology (ACOG)
- American Society of Internal Medicine (ASIM)
- American Association of Family Physicians (AAFP)
- American Association of Pediatrics (AAP)
- American Society of Urology (ASU)
- American College of Nurse Midwifery (ACNM)
- Nurse practitioners groups
- Dentists (?)

## Goals for Policy<sup>3</sup>

- # Address structural issues regarding third party payers of *reimbursement* and *referral* for DES care (including infertility treatment) and *regulation* of DES care standards (e.g., include DES care in NCQA and HEDIS standards for care).
- # Create changes in medical/nursing school curricula to include acknowledgement of the relevance and on-going nature of problems from DES. Assess current information taught about DES to providers.
- # Include health objectives for DES in Healthy People 2020 plan.
- # Provide CME/CEU for DES information courses for providers from professional societies.

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<sup>3</sup> May not be a goal of the national education campaign, but the campaign can help support the following goals for policy change.

# AUDIENCES AND BEHAVIORAL OUTCOMES

Audiences Who should we target?	Behavioral Outcomes What do we want them to do?
<b>DES Daughters</b>	
1. Known exposed <b>B</b> with or without health problems	A1. Know where to get treatment A2. Inform providers of DES exposure A3. Help providers learn proper health care guidelines A4. Get appropriate and regular health care including screening (breast and cervical) A5. Become re-educated about the continuing health risks of exposure (including potential problems associated with menopause)
2. Unknown exposed <b>B</b> with or without health problems	B1. Become aware of possible exposure by answering <b>A</b> target@questions # Born between 1938 and 1971? # Maternal history of miscarriage and/or treatment for miscarriage? # Current health problems consistent with DES exposure B2. Determine exposure status # Seek information from mother or other family member # Seek information from mother=s doctor # Try to get mother=s medical records # Try to get pharmacy records # Determine mother=s physician practice patterns # Consult own physician about whether symptoms are consistent with DES exposure If cannot rule out exposure, then A1-A5
<i>Priority audiences among DES Daughters are the known exposed and those who do not know they are exposed but have health problems consistent with DES exposure</i>	
<b>DES Sons</b>	
3. Known exposed <b>B</b> with or without problems	C1. Know where to get treatment and get a knowledgeable health care provider C2. Inform providers of DES exposure C3. Become informed of DES-related symptoms C4. Do testicular self exam C5. Get appropriate and regular health care including screening (prostate and testicular) C6. Monitor the research to be alert to continuing health risks from exposure
4. Unknown exposed <b>B</b> with or without problems	D1. Become aware of possible exposure by answering <b>A</b> target@questions # Born between 1938 and 1971? # Maternal history of miscarriage and/or treatment for miscarriage? # Current health problems consistent with DES exposure?

Audiences Who should we target?	Behavioral Outcomes What do we want them to do?
	D2. Determine exposure status # Seek information from mother or other family member # Seek information from mother's doctor # Try to get mother's medical records # Try to get pharmacy records # Determine mother's physician practice patterns # Consult own physician about whether symptoms are consistent with DES exposure If cannot rule out exposure, then C1-C6
<p><i>Priority audiences among DES sons are the known exposed and those who do not know they are exposed but have health problems consistent with DES exposure</i></p>	
<b>Women Given DES (DES Mothers<sup>4</sup>)</b>	
5. Know they received DES	E1. Tell children about exposure E2. Tell provider about exposure (increased breast cancer risk) E3. Get appropriate breast care E4. Discuss hormone replacement therapy with physician (if still prior to menopause)
6. Do not know if they received DES	F1. Determine if there is a history of treatment for miscarriage (possibility of exposure) F2. Determine exposure status # Seek information from doctor # Try to get medical records # Try to get pharmacy records # Determine physician practice pattern If cannot rule out exposure, then E1-E4
<p><i>Priority audiences among DES mothers are the known exposed, women who do not know they are exposed but have a history of miscarriage, and women who do not know they are exposed but have children that have problems consistent with DES exposure. However, mothers are often reached through campaigns targeted to daughters and sons and may not need to be a primary focus for the national education campaign.</i></p>	
<b>Health Care Providers (and students)</b>	

<sup>4</sup> Women who received DES are considered DES mothers@whether or not they have children.

<p style="text-align: center;"><b>Audiences</b> Who should we target?</p>	<p style="text-align: center;"><b>Behavioral Outcomes</b> What do we want them to do?</p>
<p>7. Who are <del>A</del>concerned@about DES</p>	<p>G1. Know where to go to get DES information  G2. Learn about DES exposure, health effects, and current standards of care  G3. Ask patients about exposure history (e.g., modify intake forms).  G4. Provide appropriate care or refer appropriately (to both medical care and consumer support groups)  G5. Monitor on-going research  G6. Act as a resource for colleagues. Be responsive to requests for help.</p>
<p>8. Who are <del>A</del>not concerned@about DES</p>	<p>H1. Acknowledge the need for continued concern about DES.  Then G1 B G6.</p>
<p><b>Secondary Audiences</b></p>	
<p><b>P</b> Third party payers</p>	<p><b>P</b> Endorse appropriate standards of care for DES exposed individuals.  (Third party payers represent both a mechanism for change as they could provide reimbursement for treatment as well as an audience for messages)</p>
<p><b>P</b> Third Generation</p>	<p><b>P</b> Increased awareness of potential problems.</p>
<p><b>P</b> Pharmaceutical industry</p>	<p><b>P</b> The national education campaign may have to develop a <del>A</del>containment@strategy to address potential opposition from this group.</p>
<p><b>P</b> General Public</p>	<p><b>P</b> Be careful about medication  <b>P</b> Get screened  <b>P</b> Develop a relationship with provider  <b>P</b> Seek health information</p>

# ORGANIZATIONAL RESOURCES

Organization	Resource
National Cancer Institute (NCI)	<ul style="list-style-type: none"> <li># Webpage (<a href="http://www.nci.nih.gov">http://www.nci.nih.gov</a>) has information on DES available through link on <b>A</b>Information for Patients, Public, and the Mass Media<sup>®</sup> (the new website will include a search engine to make location easier)</li> <li># Publications List available through website with hard copy available through DES Action (i.e., <b>A</b>rainbow books<sup>®</sup> need some revision of contact information and resource lists)</li> <li># DES National Education Project grant summary</li> <li># DES National Education Project 5 pilot site products including provider education video, various print materials etc.</li> <li># Proceedings of July meeting and appendices (will be available on website)</li> <li># <b>A</b>Blue Book<sup>®</sup> (revised and updated version of the Brown book <b>B</b> <b>A</b>How to Identify and Manage DES Exposed Individuals<sup>®</sup> <b>B</b> aimed at providers, will be available on line and hard copy. 50,000 copies will be made. Dissemination plans will be developed.</li> <li># Communication Plan Template</li> <li># Yellow Provider Toolkit</li> <li># In development <b>B</b> a bibliography of all literature published on DES since 1993</li> <li># In development <b>B</b> a list of all grants funded for research on DES since 1993</li> <li># Can include DES in the Breast Cancer Proclamation</li> </ul>
DES Action including DES Sons Network	<ul style="list-style-type: none"> <li># <b>A</b>Rainbow booklets<sup>®</sup> aimed at mothers, daughters, sons <b>B</b> more are needed</li> <li># General information pamphlet <b>A</b>DES Exposure: Questions and Answers for Mothers, Daughters, and Sons<sup>®</sup></li> <li># Booklet <b>A</b>Fertility and Pregnancy: A Guide for DES Daughters and Sons<sup>®</sup></li> <li># Booklet <b>A</b>Breast Cancer: Risk, Protection, Detection and Treatment<sup>®</sup></li> <li># Quarterly Newsletter</li> <li># Website (<a href="http://www.desaction.org">http://www.desaction.org</a>)</li> <li># Listserves for daughters, sons, and family members</li> <li># Nation wide physician referral list</li> <li># Curricula for nursing and medical students (needs updating)</li> <li># Membership <b>B</b> active participants</li> <li># Film <b>A</b>Healthy Baby Girl<sup>®</sup></li> <li># 1-800 hotline number</li> </ul>
DES Cancer Network (DCN)	<ul style="list-style-type: none"> <li># Referral list for cancer patients</li> <li># U. Chicago Registry for Clear cell adenocarcinoma</li> <li># Peer-to-peer counseling</li> <li># Website (<a href="http://www.descancer.org/">http://www.descancer.org/</a>)</li> <li># Membership <b>B</b> active participants</li> </ul>
Professional Associations including American Medical Association (AMA)	<ul style="list-style-type: none"> <li># Can make contributions in dissemination</li> <li># Websites for providers and consumers</li> <li># Technical and clinical bulletins</li> </ul>

Organization	Resource
	<ul style="list-style-type: none"> <li># Training, continuing education (CME)</li> <li># Expertise in packaging content and messages to membership</li> <li># Patient page of JAMA gets national media coverage</li> <li># Mechanisms for standard setting for membership</li> </ul>
National Women's Health Network	<ul style="list-style-type: none"> <li># Membership 12,000 <b>B</b> organizational and individual members</li> <li># Links to other membership through participation on advisory committees</li> <li># Website <b>B</b> health information clearinghouse</li> <li># Newsletter</li> <li># Annual meeting</li> <li># Listserves</li> </ul>

# POTENTIAL PARTNERS

<b>Potential Partners</b>	
Breast Cancer Organizations	<ul style="list-style-type: none"> <li># National Breast and Cervical Cancer Early Detection Program (NBCCEDP) <b>B</b> add to risk factors for breast cancer. (CDC)</li> <li># National Breast Cancer Coalition</li> </ul>
Womens Health	<ul style="list-style-type: none"> <li># Office of Womens Health</li> <li># National Womens Health Information Center</li> <li># National Centers for Excellence in Womens Health <b>B</b> 18 academic medical centers that provide training, curriculum development, and work in local communities</li> <li># National Womens Health Resource Center <b>B</b> newsletter, membership</li> </ul>
Government Agencies	<ul style="list-style-type: none"> <li># FDA <b>B</b> Dear Doctor Letters, FDA drug bulletin, may be receptive due to recent labeling of drugs for pregnancy.</li> <li># HCFA <b>B</b> e.g., promoting Medicare benefit for mammography for those over 65</li> <li># State Health Departments- Chronic Disease Divisions (not primary targets)</li> </ul>
Professional Groups	<ul style="list-style-type: none"> <li># Society for Gynecologic Oncologists <b>B</b> provides an expert resource for other primary care providers</li> <li># American Society for Colposcopy and Cervical Pathology <b>B</b> large group with goals of education and training</li> <li># Association of Maternal and Child Health Programs</li> <li># American Public Health Association</li> <li># American Medical Womens Association</li> <li># American Society of Reproductive Medicine</li> </ul>
Environmental Groups	<ul style="list-style-type: none"> <li># Environmental Protection Agency <b>B</b> interest in endocrine disruption. Will have Estrogen in the Environment Conference</li> <li># Sierra Club <b>B</b> has health committee, large subscribership</li> </ul>
Retirees	<ul style="list-style-type: none"> <li># AARP</li> </ul>

# TO DO LIST

The goal for the next six months is to develop a plan, draft messages and concepts, and test the messages for a national education campaign for DES. The following items are critical to reach this goal:

1. CDC will hire staff to develop a National DES Education Campaign that incorporates resources currently available and develops new resources as appropriate.
2. CDC will keep everyone informed (will initiate a closed listserve) and involve others as their expertise and experience is needed. NCEH OD/OC will be the central point of contact.
3. CDC will evaluate current materials in light of present objectives in terms of efficacy, utility, and accuracy. This assessment will include a detailed analysis of the information learned from the five pilot studies with specific interest in the pilot site with the target audience most similar to the one chosen by the National Education Campaign. Interviews with the principal investigators of each pilot site will be conducted.
4. With input from the DES Advisory Committee, CDC will identify gaps where formative research is needed and initiate this research within the next six months.
5. CDC will network with professional organizations to identify a realistic set of players that are willing to commit to participation in the national education campaign.

Secondary items to complete include:

6. CDC will organize a group meeting at four months (possibly the first 2 weeks of December). CDC will determine if there are sufficient funds to conduct an in person meeting or if it will be held via teleconference.
7. CDC will involve specialty organizations to develop ways to raise the ~~A~~criticality of DES for providers. AMA can help with physicians. Nancy Ridenour can assist with nurses. Involving these organizations is likely to require a personal contact such as the AMA liaisons to the specialty groups.
8. CDC will compose a smaller working group(s) around specific target groups or messages.
9. Participants will review the participant list and forward names of other resource contacts who did not attend the meeting to NCEH OD/OC. (Principal investigators on the 5 pilot projects will be a valuable resource).
10. Implementation of the campaign will be dependent upon future funding agreements between CDC and NCI.