

PARTNER AND GOVERNMENT ORGANIZATIONS

Overview

Researchers continue to learn about DES. Therefore, staying informed about DES is important for protecting your health. CDC and several partner organizations can help you stay informed about DES and related health issues through Web sites, mailing lists, and newsletters. This section of CDC's DES Update contains a list of the names and contact information for organizations that provide useful DES-related resources.



PARTNER AND GOVERNMENT ORGANIZATIONS

CDC's DES Update

CDC's DES Update

Phone: (toll-free) 1-888-232-6789

Web site: www.cdc.gov/DES

CDC's DES Update was developed as a resource for the public and for health care providers to provide them with the latest, most comprehensive, and accurate information about diethylstilbestrol (DES).

Resources for patients and consumers include

- a binder of DES fact sheets;
- DES Self-Assessment: A Guide to Understanding Your Risk for DES Exposure;
- DES Health Information Record; and
- DES Web site.

Resources for health care providers include

- DES Grand Rounds presentations;
- DES case studies;
- DES review essays;
- CME and CEU self-study modules; and
- DES Web site.

DES Advocacy Organizations

DES Action USA

610 16th Street, Suite 301

Oakland, CA 94612

Phone: (toll-free) 1-800-DES-9288 or
510-465-4011

Fax: 510-465-4815

E-mail: desaction@earthlink.net

Web site: www.desaction.org

DES Action USA is a national, non-profit consumer organization dedicated to informing the public about DES and helping DES-exposed people. This organization offers a quarterly newsletter and many publications on various aspects of DES exposure and links DES-exposed people, DES researchers, and the medical community.

DES Sons Network

Michael Freilick

104 Sleepy Hollow Place

Cherry Hill, NJ 08003

E-mail: msfreilick@hotmail.com

DES Sons Network is a national network providing information and support for DES Sons and counseling for men with testicular cancer. It is affiliated with DES Action USA.

DES Cancer Network

P.O. Box 220465
Chantilly, VA 20153-0465
Phone: (toll-free) 1-800-DES-NET-4
E-mail: desnetwrk@aol.com
Web site: www.descancer.org

DES Cancer Network is an international advocacy organization that addresses the special needs of women exposed to DES who have had clear cell adenocarcinoma (CCA) of the vagina and cervix. This network provides a support system that gives members access to one another and to information about CCA.

The DES Third Generation Network

P.O. Box 21
Mahwah, NJ 07430
E-mail: des3gen@aol.com

The DES Third Generation Network is an advocacy network designed to collect and share information about the health of children born to DES Daughters and DES Sons.

DES Sons' International Network

c/o Scott Kerlin, Ph.D.
1611 Clawthorpe Avenue
Victoria, British Columbia, Canada V8T 2R9
Phone: 250-595-6173
E-mail: scott@kerlins.net

or

Wayne Beyer, M.D.
8 East Irving Street
Chevy Chase, MD 20815-4221
E-mail: wbb3@cornell.edu
Web site:
<http://groups.yahoo.com/group/des-sons>

DES Sons' International Network is a private online professional health information and support network for DES Sons and for others with an interest in research related to DES exposure.

Other Government Resources

Centers for Disease Control and Prevention (CDC)

National Breast and Cervical Cancer Early Detection Program

Phone: (toll-free) 1-888-842-6355
Web site:
www.cdc.gov/cancer/nbccedp/index.htm

The National Breast and Cervical Cancer Early Detection Program provides information regarding obtaining free or low-cost mammograms or Pap tests; the program also provides information about risks for and early detection of breast and cervical cancers.

CDC's Reproductive Health Information Source

Assisted Reproductive Technology Success Rates, National Summary and Fertility Clinic Reports
Web site: www.cdc.gov/nccddp/drh/

This Web site contains the annual reports of the success rates of assisted reproductive technology, as well as information on reproductive health issues.

National Institutes of Health

National Cancer Institute's Cancer Information Service (CIS)

Phone: (toll-free) 1-800-4-CANCER
(1-800-422-6237)
TTY Line: 1-800-332-8615
Web site: www.cancer.gov or
http://cis.nci.nih.gov/fact/3_4.htm

CIS is a service providing accurate, up-to-date information on cancer and related issues (including DES) to patients and their families, health professionals, and the general public.

National Institute on Aging (NIA)

31 Center Drive
Room 5C27
Bethesda, MD 20892
Phone: 301-496-1752
Web site: www.nia.nih.gov

NIA conducts research about aging and provides health information to the public on issues related to this topic, including menopause, hormone replacement therapy, and osteoporosis.

National Institute of Environmental Health Sciences (NIEHS)

P.O. Box 12233
Research Triangle Park, NC 27709
Phone: 919-541-3345
Web site: www.niehs.nih.gov

NIEHS defines how environmental exposures, genetic susceptibility, and age interact to affect a person's health. The Web site contains information on DES studies among animals and research findings.

National Heart, Lung, and Blood Institute (NHLBI)

"Facts about HRT and Heart Disease:
The PEPI Trial"
31 Center Drive
MSC 2480, Room 4A10
Bethesda, MD 20892
Phone: 301-496-4236
E-mail: NHLBIinfo@rover.nhlbi.nih.gov
Web site: www.nhlbi.nih.gov

You can order a copy of this publication about hormone replacement therapy (HRT) and heart disease, by phone, through the Web site, or by e-mail.

Centers for Medicaid and Medicare Services (CMS)

"Your Medicare Benefits"

"Women with Medicare – Visiting Your Doctor for a Pap Test, Pelvic Exam, and Clinical Breast Exam"

"Medicare Preventive Services to Keep You Healthy"

Phone: 410-786-3000
Web site: www.medicare.gov

This Web site includes publications that explain Medicare's coverage of routine health screenings, as well as additional tests or procedures.