THE DES ACTION
VOICE
A FOCUS ON DIETHYLSTILBESTROL
Winter 1996 #67

Editorial

Is Managed Care Good for Your Health?

by Pat Cody

News stories about trends in health care show us that DES daughters are not the only ones worrying about a dependable health care system.

The *New York Times* reported on 15 November 1995 that

"A study of 220,000 Medicare claims has found that heart attack victims had a higher survival rate when treated by cardiologists than general practitioners.

"The finds raised concern about insurance companies' growing reliance on primary care doctors…

"Managed-care insurance plans often require that patients be seen by primary care doctors before being referred to specialists, like cardiologists. To hold down costs, such programs often include financial arrangements with doctors to limit referral to specialists."

Another story in the *New York Times* of 10 November 1995 was headlined "Drug Makers' Managed-Care Ties Questioned" and began:

"Congressional investigators focusing on competition in the drug industry said yesterday that Merck and Company had profited from the relationship with its Medco drug distribution and managed-care unit in ways that merited close attention from the Federal Trade Commission.

"Merck, as well as Smith Kline Beecham PLC and Eli Lilly & Company, paid billions of dollars over the last two years to acquire managed-care businesses, and securities analysts said the drug makers would have to increase sales of their own products to justify their investments…

"The General Accounting Office said 100 million people in the United States were in health plans served by at least 40 pharmaceutical benefits manager companies in 1993."

Another critique of HMOs was made in a letter to the *New York Times* published 19 November 1995 from Peter Meyer, president of the consumer group Scleroderma Federation. He asked, "What are HMOs doing to insure our continued health through ongoing research and discovery of better, more effective treatments for this and other 'orphan' diseases? The answer: less than nothing.

"Today, up to one-third of all bio-medical research conducted in the United States is financed through revenues from clinical income at academic centers, i.e. teaching hospitals.

"A tiny fraction of the medical bills paid at each of these centers goes to finance the continuing research that has been so critical to identifying causes and cures for disease. Last year, this tiny fraction amounted to $5 billion for biomedical research. Enter the HMOs.

"In order to keep down the short-term cost of medical care, HMOs insist that all teaching

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"Often primary care doctors know very little about DES and tell women that they can get their "gyn check-up" at the primary care office. In the cases where they will refer to a gynecologist, too often these physicians are not only not knowledgeable about the special needs of a DES daughter, but dismissive of requests for a vaginal Pap test or colposcopy."

INSIDE

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DES (diethylstilbestrol) is a synthetic form of the female hormone estrogen. From 1938 to 1971, several million pregnant women in the U.S. were prescribed DES, especially if they had a history of previous miscarriage or slight bleeding or had diabetes. DES was given in pills, injections and suppositories and sold by over 200 drug companies under their own brand names.

DES exposure can lead to health problems:

- DES mothers have a slightly increased risk for breast cancer
- DES daughters have a 1 in 1,000 risk for a rare vaginal/cervical cancer, clear-cell adenocarcinoma. This is the reason all daughters need regular gyn exams. They also are at risk for reproductive difficulties: infertility, ectopic pregnancy, miscarriage and premature delivery, and should always receive high-risk pregnancy care.
- DES sons have an increased risk for undescended testicles, cysts on the epididymus, and possibly for infertility.

DES Action, the major consumer group working on this issue since 1974, has special publications, physician referral lists, attorney referral lists, this quarterly newsletter, and a hot-line:

1-800-DES-9288.

Research Committee Meets

The DES Studies Steering Committee that will set priorities for DES research funded by the National Cancer Institute met in Washington on 3 November 1995. Representatives attended from the five research centers that have been studying mothers, daughters and sons over the past two years: University of Chicago, Boston University School of Public Health, Dartmouth, University of Massachusetts, Baylor College of Medicine, as well as from the National Cancer Institue and consumer groups.

The numbers of DES exposed who returned the extensive health surveys are shown in the chart to the right.

These questionnaires are now being computerized for analysis, and the next phase of work, analysis and report, is to be completed this year. After this, a new set of sub-studies of these same mothers, daughters and sons will begin. These studies will include:

- Menopause issues and data on bone density and calcium levels.
- Squamous cell cancer and the relationship of this cancerto sexually transmitted diseases (STDs); are DES daughters at higher risk?
- General health of third generation, plus, whether daughters of DES daughters have lower genital tract tissue changes.
- Review of pregnancy outcomes for DES daughters/controls
- Breast cancer in DES mothers/controls
- Breast cancer in DES daughters/controls
- Causes of death in DES mothers/controls
- Immune system impairment?

The committee is to meet again in April for reports on study designs.

	DES-exposed	Not exposed *
Daughters	3,860	1,713
Sons	1,240	1,254
Mothers	3,482	2,514
Total in study	**8,582**	**5,481**

*controls

letter to the editor

Dear Editor:

This letter is in response to the Illinois DES daughter who asked about lack of sexual desire.

I am also 45, as she is. My case has been mild compared to many other daughters. I have had adenosis and dysplasia, and many cervical and vaginal biopsies. I have had no surgery. For about five years, I had a lot of pain with sexual intercourse, particularly upon entry but continuing to one degree or another during the motions of intercourse. I talked to a lot of doctors about this, and nobody had ever heard of this or knew what to do. During that same period, I also talked to a lot of DES daughters who couldn't relate to my experience.

I have always had very high sexual desire, but relatively little craving for intercourse. At this point, the pain has gone away as mysteriously as it came so that's not the issue. It just doesn't do that much for me. I prefer lots of touching, embracing, and manual and oral stimulation.

This may or may not be what the Illinois daughter is looking for. I would be interested in what other DES daughters had to say, to get an idea of the range of experience.

California DES daughter

Topics in Back Issues

More recent subscribers will want to know that there are many concerns we have written about in past issues. We have had 66 issues of the VOICE before this one (1979-1995) and such topics as menopause and hormone treatment, pregnancy problems and solutions, immune system impairment, research reports, are prominent in the list.

We can send the complete listing for all back issues if you send us a stamped, addressed envelope. Back issues cost $2.50 each and you can use the list we send you as an order form.

Reproductive Technologies of the 90s

DES was the reproductive technology of the 50s. Now, many daughters from such pregnancies, whose reproductive system was affected by DES, are being urged to use the reproductive technology of this generation.

Recently the *New York Times* published four lengthy articles on "The Fertility Market" in their issues of January 7, 8, 9 and 10. We called to find out if these articles could be ordered and learned that the *Times* is sold out of the Jan. 8 and 9 issues. Accordingly, readers who want to consult this series should go to their public libraries, because most libraries do subscribe to the *Times*..

Because so many of our members want information on this subject, here is a summary of the topics covered. The first article, on "Conflict and Competition," described the market as mostly affluent, since costs can reach up to $25,000, which is usually not covered by insurance. Demand has risen, as women have delayed starting their families. The *Times* reports that in ten years the IVF centers have increased from 30 to over 300 just in the United States. They do a total of over 40,000 in vitro fertilizations and similar procedures a year, with a success rate of about 20%. The median cost of one procedure is $7,800, but the report noted that one clinic had a cost of $8,000 for which the patient was charged $11,000—a profit of 37.5%.

[We do not know how many of the patients were DES daughters: surely many of them were. A study reported nearly three

"On the roller coaster of fertility treatment, it's sometimes hard to know when to get off."

years ago, in our Spring 1993 issue (Mottla and Stillman, "Considering the Role of Assisted Reproduction in Infertile Patients exposed in Utero to Diethylstilbestrol") pointed out that a subset of the DES-exposed population has the greatest risk for reproductive problems. Daughters with uterine abnormalities have a significantly increased risk for implantation problems, preterm labor, and late pregnancy loss. Our reviewer noted that "This review also reaffirms the role of tubal disease as a factor in infertility, and in the increased risk of ectopic pregnancy." Drs. Mottla and Stillman urge that DES-exposed patients "be cautioned about the seduction of IVF, which can produce embryos, but requires transferring them into an environment that may be less than optimal... IVF and uterine transfer may be of benefit over GIFT and ZIFT, both of which require tubal transport and place the patient at risk for ectopic pregnancy."]

Egg donations are the subject of the second article. This is a relatively new, but growing, treatment for infertility and has its costs, which the *Times* states are "comparable to adoption, ranging from $14,000 to $20,000..." This procedure has its own difficulties: bidding wars and finder's fees, matching the hormonal cycles of donor and recipient through hormonal treatments, and concerns over privacy.

The third article covers the trauma of infertility, and learning to live with this condition, while the concluding article is headed, "Lives Begun in a Lab Generate Joy, Love and new Frontier of Issues." The *Times* writer points out that families using reproductive technology "are charting new territory, even revising the definition of family. When new reproductive technologies are used, each child can, in theory, have five different people with some role in creation: the woman who provides the egg, the man who provides the sperm, the woman who carries the fetus and the woman and man who raise the child. What then does it mean to be mother, father or sibling?"

In a companion article, the *Times* regular columnist on health issues, Jane Brody, writes that "On the roller coaster of fertility treatment, it's sometimes hard to know when to get off." She quotes from two women she interviewed:

"But more important than the dwindling prospects of a pregnancy or the soaring costs of treatment in deciding how far to go with in vitro fertilization was Julie Miller's state of mind. Between the mood-altering effects of hormone treatments and the ups and downs of expectations and disappointments, there was just so much of the experience she could take and still function effectively."

A second woman, Amy

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Notes from Nora

I would like to extend a very heartfelt thanks to Jeanne Gadol, DES daughter and Principal of Threshold Multimedia, for designing our beautiful new site on the World Wide Web. Jeanne volunteered her considerable design talents to produce a "home page" that we're very pleased to be able to offer as yet another way to reach DES Action.

For those of you with World Wide Web access, our locator (address) is:
http://www.desaction.org.

I invite you to visit our site and to offer any comments you have. If there's additional information you think we should include in the page, please let us know by mail, e-mail (desact@ well.com) or the good old telephone (1-800-DES-9288).

❦ ❦ ❦

On November 14, 1995 the CBS afternoon magazine show "Day & Date" aired a segment about DES which included our toll-free telephone number. On that day alone, 5,851 people attempted to get through to talk to someone on our staff. A total of nearly 7,000 calls were attempted. Unfortunately, we were only able to speak with 832 people due to limited staff and telephone lines.

The tremendous response showed us (once again) that our message is sorely needed by a public hungry for accurate information about DES and assistance with their health concerns. With your help, we hope to continue to reach people across the country in as many forms of media as possible. ❦

Our Most Common Questions

Here are the three most common questions we get nearly every day from DES-exposed people, and the very similar answers we give.

Q: Will my exposure as a DES daughter/son affect my children? Are they going to have health problems?

A: No studies have been done on the children of DES daughters and sons. We hope to get research attention this year. However, most "third generation" offspring are still fairly young. It will take many years before we have an answer—and then, only if there is still enough interest for a research study.

Q: Does DES taken with one pregnancy affect later pregnancies?

A: Again—no studies have been done. Scientists tell us that they believe this is unlikely. We will not know unless this question is surveyed.

Q: Will menopause be different for DES daughters? Should we take hormone replacement treatment?

A: Most daughters are in the "baby boom" years of 1946-1964. Although doctors began to prescribe DES from 1938 on, most prescriptions were written from 1948-1971 with the decade of the 50s the years of greatest use. Daughters from the 50s are now ages 37-46, so most of them will be approaching menopause but not yet experiencing it. We do hear from daughters about early menopause, sometimes in their 30s. However, until there is a study covering this age range, we will not know whether these early cases are coincidental or are above average for this group, and therefore related to DES.

On hormone treatment: no one knows whether taking it is risk-free for daughters. The problem of course is that by the time we find out, it will be too late to help in a decision on whether or not to use it. We suggest you carefully consider your individual risk factors for heart disease, osteoporosis, and breast cancer, and discuss them with your doctor.

DES Action Plans Reception

On March 31, 1996 the DES Action Board of Directors will honor over 20 years of DES Action work, and founder and Program Director Pat Cody, with a special reception to be held in her home town of Berkeley, CA.

A DES mother, Pat Cody has been a driving force in the DES consumer movement for over twenty years. If you have called DES Action, you have probably spoken with Pat and been educated and reassured by her calm and informative words.

Members of the DES "community" from around the country will gather Sunday, March 31 to pay tribute to Pat and to the work of DES Action. If you would like more information about this event, please contact DES Action at **1-800-DES-9288.**

HMO *from page 1...*
hospitals drop this additional fee—tiny in one patient's fee but substantial in the aggregate. Your recent article identified the HMO serving Eastman Kodak, as among those refusing to reimburse patients who choose to be treated at the local teaching hospital, despite its reputation as the best hospital in the city."

Concerns on our special health care needs

So, it does not surprise us that we are receiving an increasing number of letters and phone calls from DES daughters abut the difficulty of getting their special DES exams. Many employers are providing health care benefits through an HMO (Health Maintenance Organization) or a Managed Care system. Typically, consumers are given a limited list of primary care physicians who are in effect the "gatekeepers" for referral to a gynecologist. Often these primary care doctors know very little about DES and tell women that they can get their "gyn check-up" at the primary care office. In the cases where they will refer to a gynecologist, again there is a limited list, and too often these physicians are not only not knowledgeable about the special needs of a DES daughter, but also dismissive of any concerns such as requests for a vaginal Pap test or colposcopy.

Getting approval for an "outside" (of the system) gynecologist means an added expense for the health plan. If the DES daughter wants to see a knowledgeable gynecologist—perhaps the one she was seeing before the new "benefit" program—she is told she will have to pay for this

"Too often, health care is allocated according to the employer's budget, not the needs of the patient.

herself. Too often, health care is allocated according to the employer's budget, not the needs of the patient. Recent examples of managed care "management" include allowing only one hospital day for maternity care. Having medical decisions like this made by non-medical people so outraged some hospitals that they stated they will provide a free second day to all maternity patients. The general outcry has resulted in a backing-down on this decree.

We can learn from such an example two things: the lengths the managed care officials will attempt, and the success of organized opposition.

A particular concern we have is that some plans are allowing only one Pap test every other year. Opposition to this reduction in service was eloquently expressed by one DES Action member in a letter to one HMO:

"Pap smears are our first, simplest, and most economical defense against cervical cancers.

"Because Pap smears have a high rate of false results, frequency of use is even more critical.

"An annual schedule is easy for patients and doctors to remember as a healthy habit for preventative medicine.

"Many women at higher risk, particularly DES daughters, are not aware of their higher-risk status, and so would not normally go out of their way to ask for more regular tests."

She later wrote in more detail:

"First, some cervical cancers are linked to sexual behavior, and most women are uncomfortable calling themselves higher risk on that basis. Sexual reporting is notoriously inaccurate at the doctor's office. But also, there's a pretty large group of us who are DES daughters.... We are at a higher risk of certain formerly rare types of cervical and vaginal cancer than other women are.... Many mothers do not even know they got this drug, as in its heyday it was even added to prescription vitamins. Many daughters do not know they have been exposed.... Originally the risk was thought to be limited to women in their 20s, but now as we are all getting older it seems that similarly distinctive cancers are being found in older women as well. This is fairly new information and many doctors who claim to have knowledge about DES effects may not be aware of the latest studies...

"My own experience is that I have known since my first visit to a gynecologist in the early 1970s that I was DES exposed.... When I had some odd symptoms a year and a half ago I decided to change doctors. Two weeks after my appointment I was in the hospital having a radical hysterectomy for cervical cancer. Caught earlier, it might have been handled with an office procedure. Caught later, I might be enduring the barbaric practices that pass for long-term cancer treatment, or be looking

for a nice hospice (sorry for the tone but it's true)."

Another daughter in southern California filed suit in November against her HMO and their primary care doctor for violation of her rights:

"–Failure to provide health care to Plaintiff in a timely and appropriate manner, including the failure to listen to Plaintiff's concerns, the failure to spend sufficient time on Plaintiff's concerns and the failure to give advice, information, diagnosis, referrals and treatment for Plaintiff's abdominal symptoms and related concerns.

"–Failure to obtain and make accurate medical information and records available to Plaintiff, including results of Pap tests, in a timely and appropriate manner.

"–Allowing fiscal considerations to unduly influence medical decisions regarding Plaintiff...

"–Failure to exercise proper care in the selection, training, supervision, management and actions of Defendant Dr.____ as a Primary Care physician, as that term is defined in the Agreement."

"They have a responsibility to provide adequate care and early detection of any condition is much less expensive to manage than later discovery."

What can we do?

❦ We can write to our health plan manager asking what their policies cover in reference to annual gyn care. We can let them know that they have a responsibility to provide adequate care and that early detection of any condition is much less expensive to manage than later discovery. A copy of such a letter might be sent to the benefits administrator at your job. There is a lot of competition in this field and HMOs do not want to lose their contracts with employers.

❦ We can send copies of such letters to our state health departments and state insurance commission (addresses at your public library).

❦ We can contact women's health groups and women's centers asking them to support our letters to the state health and insurance departments.

❦ We can send our letters to the local media and call the radio talk shows encouraging listeners to join our efforts at better care.

Finally, we would like to hear from our readers on both failures and successes with their HMOs or Managed Care systems. ❦

Join DES Action!

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

❑ Benefactor: $1000 and above
❑ Sustainer: $500
❑ Associate: $200
❑ Supporter: $100
❑ Friend: $75
❑ Subscriber: $60-$30 (sliding scale)
❑ Low income: $10

All members receive **The DES Action Voice** quarterly. Those at the $100 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 of a ❑ Daughter ❑ Son ❑ Other

name _____

address _____

city _____ state _____ zip _____ phone ( ) _____

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TECHNOLOGIES *from page 4...*
Schaffer, told Ms Brody, "It can feel very courageous, empowering, to keep on trying. It fends off feelings of helplessness and feeling like a victim. There can be a strong sense of failure associated with giving up. But at the same time, keeping on trying can become self-defeating. You have to recognize when this is no longer a viable way of feeling empowered."

We addressed an alternative in the **Voice** of a year ago, "Childless or Childfree: Decision Making for a Lifetime." We invite readers to share their own experiences in letters to the **Voice**.

Your Health Record

Your Health Information Belongs to You is the title of a most informative leaflet published by the American Health Information Management Association (AHIMA). It tells you

- Who compiles your records
- Why those records are maintained
- Who owns them
- How to get access
- How to request your records
- How to keep a personal health record at home

The AHIMA is allowing us to sell this leaflet to you for a stamped, addressed envelope and $1 in cash (less bookkeeping for us). Order it from our national office: 1615 Broadway, Suite 510, Oakland, CA 94612.

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