

DES ACTION VOICE

Summer 1987

A Focus on DIETHYLSTILBESTROL Exposure

Issue #33

Clomid — Too Much Too Soon?

by Judy Turiel

If you have ever taken clomiphene citrate (CC) as a treatment for fertility problems, you may have experienced the feeling that "everyone" takes this medication. You discover that friends at work, your cousin's wife, the woman next door have also been given CC by their ob-gyn (the most common brand name is Clomid).^{*} According to an editorial in a recent medical journal (*Fertility and Sterility*, February 1987), this impression has been too close to reality.

The author, Dr. Melvin Taymor — a fertility specialist at the Harvard Medical School — describes CC as "one of the most widely used medications in infertility practice and, unfortunately, probably the most abused." (pg. 206) This medication, he states, should be prescribed primarily to infertile women who do not ovulate on their own but do produce normal amounts of the hormone estrogen. He then lists several ways in which physicians misuse CC:

1) The medication is prescribed as a "first approach," without a thorough investigation into the cause of a fertility problem, or even after testing has shown a woman to be ovulating on her own.

2) Dosage is improper — CC should be started at a low dose, with increases only if ovulation *fails* to occur (Recording basal body temperature each morning is a simple technique that

^{*} Infertile or subfertile men are also given CC sometimes, though evidence of effectiveness is lacking.

Clomid . . . one of the most widely used medications in infertility practice and, unfortunately, probably the most abused.

helps determine whether ovulation has occurred).

3) The physician fails to seek and correct possible reasons why conception does not occur when ovulation is achieved with CC. Some of the reasons, such as poor cervical mucus or

"luteal phase defect" can be caused or aggravated by the CC itself.

4) CC is used to treat the condition labelled "luteal phase defect," a condition that is poorly understood and, therefore, difficult to diagnose or treat appropriately.

5) CC is used in cases of "unexplained infertility," where no reason for a failure to conceive can be found after a thorough series of tests. The author points out that CC can have negative effects on fertility. He concludes, "The most important point is that the couple with unexplained infertility, that is, with a completely normal or negative fertility workup, have up to a 34% chance of conceiving within six months and 76% by two years without any therapy. Until control studies with CC can come close to matching these results, the therapist is best advised to refrain from the use of fertility drugs in unexplained infertility." (p. 207)

DES Action has been concerned that CC is prescribed too often, in cases where it is not appropriate for the
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Bed Resting? Need a Buddy?

Write or call our San Francisco office for names and phone numbers of women who have been on bed rest to prevent pre-term delivery. Call (415) 826-5060 between 10 and 4 Pacific time, or write to us at 2845 - 24th St., San Francisco, Ca. 94110. If we're not in when you call, leave your name, address and phone number on our answering machine tape. ■

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Get Into the Action!

DES Action USA could not have originated and grown without the dedicated efforts of volunteers. Today, we proudly boast the activities of over forty DES Action groups around the country and around the world. The foundation of each

group was created and nurtured by volunteers. *We still need you.*

Write your group today. Offer your services for a few hours a week. Become a part of the action with DES Action.

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DES Program for your State?

Once again, our faithful friends in the U.S. Congress have introduced legislation that would provide federal funds to cover some of the costs of public and professional education on DES, a voluntary registry, and provision of screening and diagnostic services. Senator Don Riegle of Michigan is sponsoring S. 169 and Representative Frank Guarini of New Jersey the companion bill, H.R. 164. They are seeking co-sponsors from every state in the union, since the funds would be given to states that set up DES programs. ■

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New Faces at DES Action USA

Welcome to Katherine Bella

We have a new national Executive Director, Katherine Bella, who moved to San Francisco from Connecticut in March. In her last position Kathy worked as Director of Development and Administration for a women's health center. Her background includes work in women's health, community organizing, lobbying, program development, fundraising and administration —

a perfect combination of the skills we need.

Kathy states, "I am so impressed with DES Action USA and the energy and commitment of our membership, locals, board and staff! I look forward to getting to know all of you better and working together to educate and advocate on a local, national and international level as well as plan for the future of our organization." ■



Kathy Bella

New Board Members

Naima Major

Naima became interested in DES Action while fundraising for the Coalition for the Medical Rights of Women in 1985-86. She presently lives in Atlanta and works for the National Black Women's Health Project, a leading health education and advocacy organization for Black women in North America.

Naima is interested in finding out more about Black women exposed to DES and believes that their experience will be instructive for all of us involved in health education and advocacy. She says, "Though I am not a DES-exposed person, I am interested in the impact of medical, specifically reproductive, technologies on women. DES makes it clear there really is no protected class of women when it comes to the excesses of medical technology." ■



Naima Major

Maureen Rafael

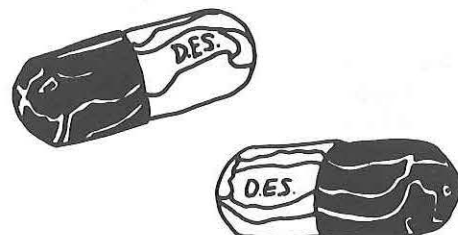
Maureen Rafael is one of the co-founders of DES Action — San Diego. She continues her active involvement in that group and is currently playing a major role in organizing the up-coming 1987 annual meeting to be held in San Diego in the fall.

Maureen initiated and coordinated the translation of both the basic DES Action pamphlet and the slide show from English to Spanish. Locally, she does a great deal of outreach and public speaking to health care professionals in San Diego County.

Maureen brings tremendous concern and energy to her new role as a Board Member. "I am honored to serve on the National Board of DES Action. Working in a pediatrics and adolescent medicine practice I am constantly reminded of the scope of our commitment, as an organization, to a DES-exposed population spanning three generations' time." ■



Maureen Rafael



"Host Uterus" — My View

by Joan Ramos

I am a DES daughter with severe uterine abnormalities. In the 10 years since we began our quest for parenthood, I have experienced infertility compounded by multiple pregnancy losses, including one ectopic pregnancy. These experiences taught us that what we really wanted was *children*; that it was not worth it to put my life on the line in the pursuit of a biological child. One of the

They point out that "host uteri" is different from surrogacy, since the "host" has no genetic connection to the child. But is it really so different?

losses that we experience in infertility is the loss of our genetic child. Dealing with this loss is part of our grieving process. Through international adoption, my husband and I became parents. Our children are now school age. My DES exposure and complications of infertility continue to pose chronic health concerns for me, and adoption did not cure my infertility. I have become the wiser from my situation, and yes, I can live with it.

Therefore, I have been appalled to read about "host uterus" programs at In Vitro Fertilization (IVF) centers. They refer to the "host uterus" as if a uterus were an entity of its own, not part of a female human being. They point out how this technique is different than surrogacy, since the "host" has no genetic connection to the child. But is it really so different? They fail to mention just who are the women who offer their uteri as "hosts," how

much they are paid, and how much the infertile couple are charged for this "service." My latest DES Action VOICE issue states that between 7-10% of women of child-bearing age in the U.S. have been exposed to DES; an estimated half of us will have infertility and/or pregnancy problems. All of us are "victims" of a society that defined a woman's role and worth by child-bearing capacity, in cooperation with the medical profession and pharmaceutical industries that sought a convenient and profitable tool to enable our mothers to achieve this role. Let us not, in our generation, turn around and perpetrate another mistake on another group of women who would be employed as breeders for us.

I have never seen data on the correlations between social class and rate of DES exposure, but anecdotally have heard it is primarily a middle-class phenomenon. That is, DES was mainly given to pregnant women seen in private practice, who were receiving the "best" prenatal care at the time. If the majority of DES-exposed offspring in the U.S. today are white, middle or upper class, and college educated, it is pure arrogance for "us" to insist that whatever means possible be afforded us in the quest for our supposedly superior genetic children. ■

Public Service Praise for Wisconsin Leader

Laila Rosen of our Milwaukee chapter has been honored by the Wisconsin Academy of Trial Lawyers and the Association of Trial Lawyers of America (ATLA). Ms. Rosen was presented with their Victim Service Award at a special May luncheon. The award was given for her work in establishing DES Action in Milwaukee and her activities with pharmacies throughout the state to distribute information about DES. The President of ATLA said that the award to Ms. Rosen, and to two other community leaders, are "an important part of ATLA's continuing commitment to asserting the rights of injured victims. These nominees have all contributed to the advancement of human rights, and I am very proud that ATLA is recognizing them with these awards." ■

DES Action at International Conference

DES ACTION/Canada had an opportunity to "promote the group and the issue amongst health professionals from all over the world," according to Shirley Simand. At the International Conference on Health Promotion held in Ottawa last November, DES Action was one of only 40 groups chosen by the sponsors, World Health Organization and the Canadian government, to have a display booth. As Shirley said, "We were an

example of a grass-roots organization filling a need not provided by either the government or the private sector."

Contacts made at the conference have led to invitations to address other health groups within Canada. The good impression was international: the Health Policy Advisor for Hungary, Dr. Michael Kokeny, visited the national office of DES Action/Canada in Montreal while visiting there. ■

Understanding Pap Tests

There are certain words that seem designed to scare us — "pre-cancerous cells," "dysplasia" and "carcinoma in situ"; these are words that are often mentioned but not explained by a confident doctor who may already be taking a biopsy without explaining the terms.

Thankfully, the women at the Vancouver Women's Health Collective have produced an extensive 40-page booklet designed to demystify all of this. "Feminist Approach to Pap Tests"

is remarkably clear and easy to read. Every stage of a pap test, from preparations to results is discussed. The various classifications are explained so that women can understand the results as they come back from the lab. Special circumstances, i.e. pregnancy, infections, etc. that may alter results are also dealt with.

The emphasis is placed on taking the time to discover, interpret the results, and to choose the best course of action. There is also due attention paid to self-healing in terms of changes in diet, vitamin intake and other variables that may affect results. Although the booklet offers no miracle solutions, it does provide options to the treatments often prescribed as a matter of course in some cases. Barbara Mintzes, a member of DES Action/Canada who helped research the booklet, said that while some of the information is specific to British Columbia, "it could be applied elsewhere. The statistics are probably not very different." Copies can be obtained by sending \$3.50 to: Women's Health Collective, 888 Burrard St., Vancouver, B.C. V6Z 1X9, Canada. ■

United Way Donor Option

DES Action is a member of the United Way Donor Option Program, a plan which allows employees to earmark their United Way payroll deduction funds to a specific organization. Please remember us when a United Way representative visits your workplace this summer or fall. ■

Hysterectomy Information

We've learned about a self-help group that will be of interest to many of our readers. It's the HERS Foundation — Hysterectomy Educational Resources and Services. The HERS Newsletter (\$15 year) gives information about options, after-effects and coping techniques. Its goal is to help women take control of their bodies and their lives by getting the information and support they need in making decisions about this surgery (or non-surgery). HERS also sponsors an annual conference. For a list of the topics covered in back issues, and more information, send a stamped envelope to HERS Foundation, 422 Bryn Mawr Ave., Bala Cynwyd, Pa. 19004 (215-667-7757). ■

DES Action Receives Major Foundation Grant

DES Action has recently been awarded \$30,000 from the Sumner McKnight Foundation of Minneapolis. We will use most of this generous grant for our important public outreach work. From the responses we receive from media coverage, we are aware of the thousands of people who still are not informed about their exposure.

The McKnight money will be used to:

- **Plan** and produce a new national television public service announcement;
- **Write and print** a new sons leaflet, and distribute it to urologists across the nation;
- **Send** our Reproductive Outcomes booklet to physicians, clinics and nursing schools;
- **Provide** basic informational materials to college health services;
- **Collaborate** in a national research conference in 1988, "50 Years Experience with DES." ■

Resource for New-Borns

Parent Care is a non-profit organization composed of parents and professionals dedicated to improving the newborn intensive care unit experience for critically ill newborns, families and professionals. The organization offers information, referrals, and other services to families, parent support groups, and professionals concerned with infants who require intensive or special care at birth. For more information write to Parent Care, University of Utah Medical Center, Room 2A210, Salt Lake City, UT 84132. ■

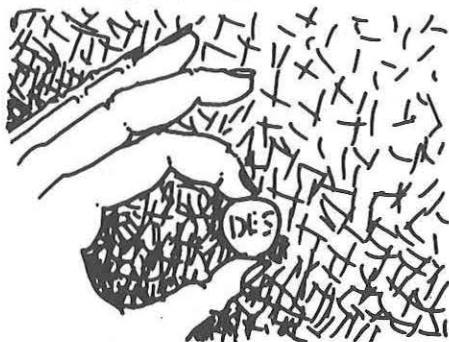
Dear Doctor

Letters

Q: What is known about fallopian tube problems in DES daughters? I am a DES daughter with adhesions in my fallopian tubes. These adhesions were diagnosed during an infertility work-up. What are the treatment options for this condition? Are there any side-effects to surgical treatments?

A: Little information exists about fallopian tube problems in DES daughters. Anecdotal reports have suggested that the tubes may be malformed in a *small* number of patients. While the tubes appear normal in most patients, both by external examination through laparoscopy or internal through hysterosalpingography, many patients have evidence of the tubes not functioning properly by a much higher incidence of ectopic tubal pregnancies in DES daughters. I know of no information or data to suggest that adhesions in the tubes are in any way associated with DES exposure. If adhesions are present, then treatment options are the same as those for a patient who had not been exposed to *in utero* DES, namely surgical lysis (cutting) of the adhesions through a laparoscopy if possible, and if not, through tubal surgery. Cryosurgery is not a form of treatment for tubal disease. Side effects from surgical treatment are — as best we know, no different in DES-exposed patient from the patient not exposed.

Robert J. Stillman, M.D.
Associate Professor
Director, Reproductive
Endocrinology and Fertility
George Washington University
Medical Center,
Washington, D.C.



Pregnancy Stories

Dear Editor,

I want to add my success story in hopes of encouraging other DES daughters.

In 1978 I had a cone biopsy to remove my cervical adenosis, probably caused by my mother taking DES. Four years later, when my husband and I tried to get pregnant, we discovered that my cervix was scarred. Not only did this act as a barrier to the sperm, glands that secrete a mucus that help the sperm were damaged by the conization.

After seeing four doctors, we were lucky to get in contact with a doctor who was doing inseminations by first washing the semen, both thinning it and making it more acceptable to the woman's uterus.

After three months of having my cervix dilated before ovulation, and then being inseminated with my husband's sperm, I became pregnant. Unfortunately, this pregnancy ended with miscarriage at eight weeks. Months later, we began the process again. I became pregnant on the first try.

As I write this, my four-month-old healthy, beautiful daughter sits across from me, smiling and babbling. She was worth it all.

Sincerely,
G.B.
California

Editors' Note: The following is a personal story by a DES daughter about her difficult pregnancy experiences. This story, like many others, dramatizes the special irony for DES daughters — having to make difficult decisions about the risks and benefits of fertility and pregnancy treatments. We are pleased about the happy ending to her story. We do think that it is important to remember that the recommendations of her physician may not be what all doctors would have prescribed. There is no definite fertility "plan." We all need more information about the various treatments for fertility and pregnancy problems.

Dear Editor,

Since DES Action helped me with information, both via phone and the newsletter, during the hard times after I suffered two second-trimester pregnancy losses, I would like to share the good news. Our daughter was born in March, two days before her due date and weighing 8 lbs. 15 oz.

This feat was achieved with the help of a very special doctor experienced with the problems of the DES-exposed. He did a sort of double cerclage when I was 9 weeks pregnant. I used progesterone suppositories until my 13th week of pregnancy and had weekly Delalutin shots after that (a hard decision to use this hormone, but I could uncover no evidence in the literature of harmful effects).

Because of cramping I was on "couch rest" from my 15th week until my 32nd week when it stopped. I took Motrin to stop the cramping and never needed to be hospitalized for premature labor. My doctor performed bi-weekly ultrasounds to check my cervix for effacement. Very important to my emotional well-being during my pregnancy, my doctor saw me every week from my 15th week on. I cannot stress enough how important it is to have a doctor experienced with the pregnancies of DES daughters.

Because it would have helped me to know, I would like to add that despite getting pregnant easily the first two times, I was unable to get pregnant in two years of trying after my second loss. My husband and I finally gave up temperature charts, Clomid and trying and went on with our lives. Six months later I got pregnant.

S.B.
Ann Arbor, Mich.

Class Action Suits?

Dear Editor,

My daughter is a DES daughter. I joined DES Action because I wanted to keep track of any class action suits that might be started to cover expenses of extra medical exams required.

I don't remember seeing anything in your newsletter regarding law suits,
continued on page 7

Letters from page 6 . . .

class action or otherwise. I hope you will consider including such info in the future.

Keep up the good work!

G.P.

Santa Barbara

DES Action responds:

There are no class action suits against the drug companies in the U.S., nor are there likely to be. In order for a class action to proceed in the courts, a judge must first certify that a genuine "class" exists under the meaning of the law. Class actions are designed to save time and money by, for example, joining suits for similar injuries into one suit. In the case of DES, the spectrum of injury is very broad. On the one end are DES daughters with adenosis and annual medical bills for their regular exams, but no other physical changes that they are aware of. On the other end are DES daughters with cancer or with other serious problems such as T-shaped uterus, infertility, stillbirths, miscarriages, and ectopic pregnancies.

Accordingly, DES daughters who do have injuries are suing, under product liability laws, as individual plaintiffs. These are contingency cases: your lawyer only gets a fee if the suit is successful. That means lawyers cannot afford to take cases unless they believe that they can win. The categories of suits currently being taken by lawyers are for cases of cancer, infertility, and "pregnancy disaster" — tubal pregnancy, miscarriage, premature birth, stillbirth.

Polluters Pay

Thanks to Jeff Lake of Santa Clara Center for Occupational Safety and Health in The Silicon Valley Toxics News, Spring 1987.

Across the nation, people are awakening to the horrors of toxic contamination in their communities. Many have organized to bring lawsuits against the polluters in an attempt to exact some measure of justice under the law. What follows is a brief update on some of these cases and conclusions we can draw from them.

The case that has sent the greatest shock waves into the board rooms of the major polluters was against Monsanto, where a Federal jury in Houston, Texas recently awarded **\$108 million** to the family of a chemical worker who died of leukemia after working with benzene for several years. The verdict — the largest known of its type — was unanimous, giving the survivors \$8 million in actual damages and \$100 million in punitive damages.

In cases involving dioxin contamination in Times Beach, Missouri a \$19 million settlement has been proposed involving the first 128 cases. There are still over 1,500 more claims still pending.

In Boston, a settlement was reached with W.R. Grace & Co. involving toxic contamination of drinking water wells in Woburn, Massachusetts. The terms of the settlement were not made public, but more than \$10 million was said

to be involved. Grace admitted no liability.

Finally, in a suit involving toxic contamination in the Los Paseos neighborhood of San Jose, plaintiffs announced in July that they had reached a settlement with Fairchild Semiconductor Corp. The terms were kept confidential, but the award was a multi-million dollar one. Fairchild admitted no liability.

All of this goes to show that the real answer to toxics litigation is prevention. Lawsuits are never a solution, but only point to the fact that more needs to be done. Until the polluters change their ways, however, we as citizens and potential victims must continue to assert our rights. So-called "tort reform" must be unmasked to show what it really is; a clever deception to remove one of the most powerful weapons the public has to hold polluters accountable for their actions and provide incentive for prevention. Don't be fooled, the problem is not crazy juries, greedy lawyers and a tort system run amok. For, as Paul Brodeur has remarked, "If we buy that nonsense, if we give up our precious rights for the privilege of not being blackmailed by the nation's insurance industry, we will in effect have issued the manufacturers of toxic chemicals and hazardous substances a license to kill. If we do that, will we not one day exclaim, wide-eyed as Pogo, that we issued them the license and, lo and behold, the big game was us?" ■

JOIN DES ACTION

Enclosed is my tax-deductible membership. All members receive a copy of the *DES Action Voice* four times a year. Make checks payable to **DES Action** and mail to:

Long Island Jewish Medical Center, New Hyde Park, NY 11040.

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annual reports on DES Action's work and progress.

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I am a ☐ DES Daughter ☐ DES Son ☐ DES Mother ☐ Other

Clomid *from page 1 . . .*

particular couple attempting a pregnancy. In addition, some scientists have raised the possibility of effects on a baby conceived during a CC cycle. Since DES-daughters do experience increased rates of reproductive problems, one concern is, of course, for this group of women. More generally, however, we are concerned that this medication has become a popular and easy treatment that, like DES in the past, physicians routinely apply. Unlike DES, CC can be an effective treatment in certain cases — some women who do not otherwise ovulate will do so after taking CC. However, this medication is clearly used far more often than it should be, in cases where benefits either do not exist or do not justify the undesirable side effects and unknown risks.

If your doctor recommends CC, you can ask questions that address the abuses outlined above:

- **Does the doctor think you are not ovulating? What tests have been done to demonstrate this?**
- **If you are ovulating, why does the doctor want to prescribe CC?**

- **What benefits, if any, will CC have for you, and what about possible adverse effects on fertility (for example, lowering the quality of cervical mucus). In other words, what are the risks and benefits of this treatment in your case?**
- **What dosage schedule is planned? What other tests or therapies will be considered if you ovulate after taking CC but do not become pregnant?**
- **Are there other approaches that might be more suitable in**

your case? (For example, physicians at some medical centers now use an "ovulation pump" for women who do not otherwise ovulate — See Voice issue #30)

It is encouraging to see a physician warning his colleagues about their frequent misuse of a medication. Unfortunately, this discussion appears in reading material that most patients never see. Patients can help avoid inappropriate treatment only if they are provided with accurate, full information and know what questions to ask about their particular situation. ■

Litigation:

Wins and Losses

DES daughters in two states have had widely different outcomes in their product liability claims against the drug companies. Julie Shirkey, who had surgery in 1982 for clear-cell cancer, sued Eli Lilly in Federal Court in Milwaukee. An all-woman jury of eight decided that Lilly was not negligent in marketing DES in 1960, and that the DES taken by the plaintiff's

mother was not defective.

In Illinois, however, another Federal jury upheld an \$800,000 damage award to Anne Needham in a retrial of the case, originally tried and won by Needham in 1979, against White Laboratories. Needham had surgery for clear-cell cancer in 1973 — it has taken 14 years to reach her victory. ■

DES Action USA

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