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Winter 1989

#39

When is Enough Enough?

by Andrea Goldstein

n the United States one couple out of six is infertile. Each year these millions of couples spend one billion dollars in their quest for pregnancy. Today, medical advances will help one-half of these couples achieve biological parenthood. Great strides have been made in both the diagnosis and treatment of infertility. Doctors today possess a whole range of therapies, ranging from the simplest, such as helping couples to time intercourse more appropriately, to the most technologically advanced, the creation of the first stirrings of life via in vitro fertilization. A whole raft of ofther treatments and surgical procedures is also available.

Fifty years ago, couples unable to conceive had little in the way of diagnosis and treatment. Of necessity they spent very little energy in pursuit of pregnancy, and therefore had to come much more quickly to an emotional resolution of their infertility.

Today, couples can spend literally decades trying to cope with what is surely an essential life issue.

Limits and Pressures

While all infertile couples pursuing pregnancy need to ask themselves "when is enough enough?" the DES-exposed couple is caught up in an even more complicated web. Victims of a so-called 'medical miracle,' we may struggle even more as we consider not only 'traditional' therapies, but the new technologies as well. All too many of those of us who desire to reproduce get 'hooked' on infertility: not only the childless, but those experiencing secondary infertility as well as those who have built their families through adoption.

Certainly, every infertile couple who wishes to should pursue available medical options that could lead to conception. The difficulty lies in setting

reasonable limits on what we will do. A varity of pressures, both internal and external, impede our ability to get off the 'infertility treadmill.' For some, family pressure is great. Often one member of the couple wants to stop treatment, only to be pressured by the other to continue. Some women who are mothers through adoption still feel incomplete because they never achieved a successful pregnancy of their own. These women often return for treatment of their infertility problems despite the fact that their husbands are happy with their families as they are. For other women and couples, stopping therapy is itself paralyzing because so much time, energy, focus and even self-worth have become bound to being actively engaged in the 'job' of infertility treatment. Furthermore, ceasing therapy means that the woman or couple experiences a further continued on page 4

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"Worse than Disease"

Doctor-Patient Relations

Incompetent Terminology

Voice Subscription Rate Increases to \$25

ecause of higher printing and overhead costs over the last four years, the VOICE subscription rate is increasing to \$25 - 50 per year effective in January 1989.

The VOICE will continue to

serve as your line to what is new and relevant in DES research, medical care and publications, as well as providing a forum for sharing personal stories and concerns.We thank you for your continued support.

Get Into 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 across 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.

DES Action/USA National Offices 2845 24th Street San Francisco, CA 94110

Long Island Jewish Medical Center New Hyde Park, NY 11040

California c/o Dr. Wingard Community Medicine M-007 Univ. of Calif-S.D. La Jolla, CA 92093 417 Avenida Abetos San Jose, CA 95123

Colorado P.O. Box 2645 Colorado Springs, CO 80901

Connecticut c/o Montes 14 Dodge Street New Britain, CT 06053

Florida 4425 N.W. 113 Way Coral Springs, FL 33065

Georgia 580 Spender Trace Dunwoody, GA 30350

Iowa P.O. Box 14 Iowa City, IA 52240 Kansas

c/o Lester 601 S. Elm Ottawa, KS 66067

Louisiana P.O. Box 804 Chalmette, LA 70044

Massachusetts P.O. Box 126 Stoughton, MA 02072

Michigan P.O. Box 2692 Ann Arbor, MI 48106 2205 Rosewood SE Grand Rapids, MI 49506

Minnesota c/o YWCA 1130 Nicollet Mall Minneapolis, MN 55403 Missouri 7647 Carswold Clayton, MO 63105

New Jersey 108 W. Palisades Ave. Englewood, NJ 07631

New York P.O. Box 331 Brooklyn, NY 11229-0331

> Box 597 Fishkill, NY 12524

Box 67681 Rochester, NY 14617

Ohio P.O. Box 26091 Akron, OH 44301 286 Jenny Lane

Centerville, OH 45459 Box 21625 Cleveland, OH 44121

Oklahoma 9712 E. 55th Street Tulsa, OK 74146

Oregon c/o Akkerman 718 W. Burnside Portland, OR 97209

Pennsylvania P.O. Box 6 Lenni, PA 19052

Texas
5638 Merrimac Ave.
Dallas, TX 75206
3152 Gardendale Dr.

Port Neches, TX 77651 8230 Shadowwood Drive

Waco, TX 76712 Wisconsin

P.O. Box 17102 Milwaukee, WI 53217 Washington

P.O. Box 2547 Olympia, WA 98507 DES Cancer Network P.O. Box 10185 Rochester , NY 14610

DES Action/Canada National Office 5890 Monkland, Suite 104 Montreal, Quebec H4A 1G2

Alberta

316-223 12th Avenue S.W. Calgary, Alberta T2R 0G9

Nova Scotia Box 311

Greenwood, N.S. B0P 1N0 NW Ontario

c/o Women's Health & Info Network 8A North Cumberland St. Suite 17

Thunder Bay, Ont. P7A 4L1 Ottowa

Box 11091, Station H Nepean, Ontario K2H 7T8

Quebec 5890 Monkland, Suite 405A Montreal, Quebec H4A 1G2

Saskatchewan 11 Laubach Avenue Regina, Sask. S4A 6C3

Toronto Room 442, Burton Hall 60 Grosvenor Street Toronto, Ontario M5S 1B6

Vancouver c/o Women's Health Coll. 1720 Grant Street Third Floor Vancouver, B.C. V5L 3Y2

Winnipeg c/o Women's Health Clinic 419 Graham, 3rd Floor Winnipeg, Man. R3C 0M3

DES Action/Australia P.O. Box 282 Camberwell, Victoria 3124 Australia

Action DES France 25 rue Croix de Bois 45000 Orleans, France

DES Action/Netherlands DES-Aktiegroep Maliesingel 46 3581 BM Utrecht The Netherlands

Survey of DES Daughters

Professor Lucinda Finley, who teaches tort law and feminist legal theory at Yale Law School, writes to us:

"Drawing on these two subjects, I am writing a book about the DES tort litigation from the perspective of women injured by their exposure to DES. These stories, which have not sufficiently been told, are worth telling to validate the experiences of DES daughters, to shed critical light on the way in which the legal system deals with injured people, and injured women in particular, and to inform the public about what DES, the drug companies, and the legal system have done to women.

I want to send a survey to DES daughters, including cancer victims as well as women injured in other ways, who would be

I am writing a book about the DES tort litigation from the perspective of women injured by their exposure to DES

interested in sharing their story with me. Any desire for confidentiality will be fully respected. If you are interested in helping with this work, please write to me at:

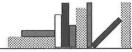
Lucinda Finley
The Bunting Institute
of Radcliffe College
34 Concord Avenue
Cambridge, MA 02138
I will be at this address, where
I have a fellowship to work on
the book, until June of 1989.

The DES Action Voice is published quarterly by DES Action USA 2845 24th Street San Francisco, CA 94110 Program Director: Pat Cody Board Officers President: Kari Christianson VP: Maureen Rafael Secretary: Shirley Simand Treasurer: Libby Saks

Contributors:
Pat Cody
Andrea Goldstein
Joyce Bichler
Ellen 't Hoen

Design and Layout: Kristin Prentice/ Sphinx Graphics Berkeley, CA Printing:

Printing: Inkworks, Berkeley, CA



book review

Worse than the Disease: Pitfalls of Medical Progress

by Diana B. Dutton, Ph.D.; Cambridge University Press, \$29.95.

ES is one of the four "pitfalls of medical progress" examined in this extraordinarily well-written book; the others are the swine flu vaccine, the artifical heart, and genetic engineering. Dr. Dutton looks at these four drug/biotechnical innovations to find out what policies were made, by whom and why, how some policies aggravated problems rather than solved them, and what can be done in the future to safeguard the public.

Our interest, naturally, focuses on "DES and the elusive goal of drug safety," where the issues explored include the history of the development and regulation of DES, the Food and Drug Administration's role ("public protector or corporate coach?"), the failure of regulatory safeguards, and extensive description of DES use in pregnancy until the cancer link was made in 1971. In her conclusion to this section, Dr. Dutton writes:

Could the DES story happen again? Without some major realignment of the forces that dominate medical and scientific innovation, the chances seem very good—not in precisely the same form, to be sure, but with the same underlying causes and similarly poignant consequences. If the DES story is any guide, the best hope of avoiding such an event lies in strengthening government regulatory and enforcement mechanisms, in pay-

ing more attention to those whose warnings were ignored in the past - disinterested scientific critics, consumer advocates, and independent Congressional committees—and in increasing public awareness of the risks of medical and scientific innovation and the limits of present safeguards. Such steps are not foolproof, but they deserve to be tried.

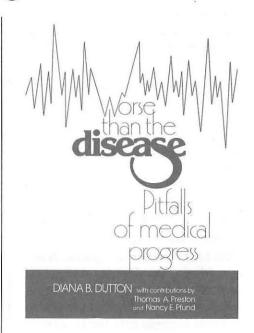
In the heart of the book, "Lessons, Questions and Challenges," the author states:

All medical advances involve risks. Nothing ventured, nothing gained, as the saying goes. But that does not mean all risks are worth taking, or that we would all make the same choices. In at least two of the four case studies, DES and swine flu (and some might add the artifical heart), the risks were definitely not worth running, a judgment some observers made at the time. The periodic public controversies over genetic engineering also underscore the wide differences in people's responses to, and even definitions of, risks.

There is an excellent section on "compensating the injuries of medical innovation" in which Dr. Dutton argues that

It seems unjust to expect individuals to bear these costs without compensation, since they are often unaware of the risks they are taking and have little voice in deciding societal policies on innovation... Ideally, our society would assure all citizens of reasonable health and disability benefits when they are sick or injured. But there is an additional reason for compensating victims of human intervention. Society as a whole has a stake in assigning to those responsible the costs of injuries inflicted through human action, since the resulting deterrent effects theoretically produce a more socially efficient, as well as equitable, allocation of resources.

The chapter on "the role of the



public" discusses reassessing risks and benefits, broadening and humanizing biomedical policy, democratizing decisions, and the impact of public efforts. The work of DES Action is described, and the section concludes:

A crucial factor in DES Action's success has been the intense commitment of the women involved, many of whom have been personally affected by DES. The consequences of DES exposure are frightening and potentially lethal. Ties to the women's health movement helped transform these personal fears into political action. Women's health activists, all too familiar with being marginal to mainstream medicine, financially threatening to the drug industry, and low priority for the federal government, have schooled DES advocates in the tactics of self-help through collective action, sharing resources and contacts. DES Action has also benefited greatly from the involvement of compassionate physicians. But it has

continued on page 6

ENOUGH from page 1 . . . loss of control: already unable to control their infertility, they get comfort from being the masters of their treatment, at least to the point where technology ends.

Hope and Reality

Some couples fail to realize, however, that the prospects held out by modern treatment methods may be more hope than promise. The new reproductive technologies are a case in point. While indeed successful for a few couples, most will not achieve pregnancy by going this route. Nonetheless, these methods are tempting to so many. Perhaps this is because these pursuits provide one more way couples can avoid, if only for a brief time, facing the question of when to let go. Desperate for success, couples often fail to take into account the reality that the optimal success rate for in vitro fertiliation (IVF) is only 15%. Unfortunately, many IVF centers,

Often overlooked are the physiological effects of long-term treatment

focusing on their success rather than their difficulties, do not present the entire statistical story. Couples can thus be misled to seek these alternatives at any cost—physical, emotional, financial.

For DES daughters, even the 15% pregnancy rate at the most successful centers is misleading. This figure is based on the ideal IVF candidate, one whose problem is limited to an absence or a blockage of Fallopian tubes. The reality for the DES exposed wo-

men is that her reproductive problems are often far more complex, thereby drastically decreasing even further the already slim possibility of success.

Problems with Treatments

Also often overlooked are the physiological effects of long-term treatment. Infertility testing and procedures can be stressful. Many therapies carry with them uncomfortable side effects such as nausea, dizziness and ovarian pain. Some therapies, such as Pergonal, can become full-time jobs because of requirements for many office visits, lab tests, and self-administered injections. They also carry with them the risk of miscarriage and multiple gestation. Furthermore, for those who do become pregnant, the near 7-fold increase in ectopic (tubal) pregnancy among DES daughters means a very real possibility of major surgery or even death. In addition, our risk of premature birth (15% vs. 5% in the general population) makes us vulnerable to those physicians who would choose to help us maintain our precious pregnancies with a plethora of pharmacological agents ranging from progesterone to terbutaline. Some of these agents are of no real value, some are known to be ill-advised, and some may have long range effects to be discovered perhaps decades from now.

Moving On

How, then, can we move on in our lives, or help others to do so? Sometimes the pain involved in being infertile, and the extent to which people deny that they might not be able to overcome it, makes it more difficult to examine the very questions that might help them move on. But they must examine them, for there is a real possibility that they may not achieve a successful pregnancy, that the dream child they have hoped for may never be. This awakening, while extremely painful, need not keep them from restoring their lives.

What are the psychological effects tied to the inability to move off the infertility treadmill? To what extent should a couple put their lives 'on hold' for want of pregnancy? This holding pattern is particularly true for the woman, who will postpone furthering her education or turn down promotions or job offers because she continues to hope that pregnancy and parenthood lie just around the corner. Sometimes this endless pursuit drives a wedge between otherwise loving devoted partners, resulting in separation or divorce. For others, the options of either a child-free life or adoption seem so terrifying that retreating to the 'safety' of the infertility specialist becomes the only way to obtain some emotional relief.

Lynda Rutledge Stephenson, in her book Give Us A Child states:

The quest carries with it a sort of 'grief on hold,' an ongoing numbing sort of grief you keep pushing back, pushing back. And because of this innate sort of defensive reflex, a healthy grief process may be possible only when the couple, yearning for resolution, choose to experience it by ending the testing themselves.

For those couples who do finally decide that 'enough is enough,' there will be pain and grief, but in the end there will be a peace that can only be achieved once they let go of the dream and realize that it is in fact possible to move on without something they wanted very much.

DES Action:

Its Influence on the Awareness, Experiences and Doctor-Patient Relationships of DES Daughters

by H.A.M. Zalmstra, E.F.M. 't Hoen and A. Visser

ontact between DES daughters and DES Action seems to be important in terms of their personal experiences and behavior, as well as their doctor-patient relationships. Doctors conduct better medical examinations and give more information and their patients are more assertive, thanks to DES Action. This is the most important conclusion from a survey conducted by Dr. Zalmstra (social psychologist from the University of Amsterdam, Ms 't Hoen (from DES Action the Netherlands) and Dr. Visser (social psychologists from the University of Limburg).

Patient rights organizations

Doctors conduct better medical examinations and give more information and their patients are more assertive, thanks to DES Action

can have an important function in health care. When patients organize themselves and adopt an active and emancipated attitude, they play a crucial role in changing the power relationship between doctor and patient which is all too often asymmetric. They organize because they have a need for information, a need for sharing experiences, and a need to vindicate patients' rights. DES Action is an example of how a patients' rights organization can criticize the health care system in a constructive way. It was DES Action that publicized the DES controversy that had been silenced by doctors in the Netherlands for ten years.

The medical aspects of DES are well researched in the United States. However, little is known about the experiences of DES daughters. This article describes the results of the first Dutch research into the experiences of DES daughters and their participation in DES Action. The research focuses on how contact with DES Action influences DES daughters' awareness and control of their health. It also studies how the relationship between DES daughters and their gynecologists is affected by patients' contact with DES Action.

DES Action at Work

In the Netherlands, the DES problem only came to light in 1981, even though DES had not been prescribed for use in pregnancy after 1975. It was brought to public attention by DES Action, an organization of DES daughters and mothers.

Through publicity and pressure on the government, the organization seeks the implementation of policies concerning the



tracing, informing, examining and treating of the DES exposed. The group also wants the DES story to serve as an example in the hope that this will decrease the chances of similar mistakes by the medical profession in the future. DES Action provides information brochures, a telephone line and the DES News Bulletin for people concerned about DES. The telephone line is also used for emotional support. Across the Netherlands, regional contacts organize disucssion and information meetings that are held regularly.

Thanks to the activities of the action group, more and more attention is being paid to the DES problem by people in and out of the medical profession. The founding of the DES Network is proof of this. The Network is a group of gynecologists that specialize in the screening of DES daughters. There is regular consultation between these specialists and DES Action. How-

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PITFALLS from page 3...

been DES Action's ties to its local constituents that are its greatest source of strength. This community base has kept the organization publicly accountable while allowing it to flourish entirely outside any formal structure of government, academia, or industry. With this base, DES Action has shown growing numbers of women how to take political as well as personal control of their medical destinies.

In her final chapter, "Toward medical progress in the public interest," Dr. Dutton sees the central dilemma of biomedical "progress" as the lack of public accountability, and concludes

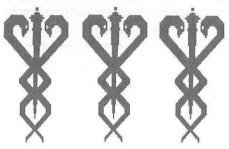
NETHERLANDS from page 5... ever this does not change the fact that there are still doctors, both family practitioners and gynecologists, that don't know enough about DES and its consequences. Therefore, the complaints of DES-exposed women are not taken seriously and they are not receiving the information to which they have a right. On the other hand, unnecessary and sometimes dangerous overtreatments of DES daughters can occur. Thus part of DES Action's efforts are directed towards educating doctors. Their efforts also result in influencing doctors indirectly by informing DESexposed women and encouraging them to be more assertive.

Fifty-two DES daughters have taken part in this research: 40 from the DES Action contacts list and l2 daughters who are active in DES Action at a regional level. The group was extensively interviewed. Questions dealt with biographical information, medical knowledge about DES, feelings of powerlessness, and attitudes toward DES.

The information on the doc-

that medicine must be made more publicly accountable. We would broaden that to include the pharmaceutical industry as well as the federal departments involved in health issues.

By putting the DES experience in the context of other "pitfalls of medical progress," Dr. Dutton has shown us that we are not alone in having a cure "worse than the disease," and that it will take the concerted efforts of the public and the political institutions that serve us, to create a more responsible medical establishment.



tor-patient relationship was arrived at through questions about the doctor's examination, the information given by the doctor, how the DES daughter judged this information, the socio-emotional support provided by the doctor, and the patient's satisfaction with the doctor in various areas.

Medical Knowledge and Education

The difference in medical knowledge between doctors and patients is the most important reason for the asymmetrical power relationship. Knowledge is power. In order to balance the misunderstandings in the relationship, the women's health movement has aimed at giving women more knowledge and, therefore, greater control over

their bodies.

The question that must be asked now is "is DES Action successful in giving DES daughters information on DES?" This question can be answered positively. Our study found a strong relationship between participation in DES Action and medical awareness of DES. Most of those interviewed indicated having received the information on DES from DES Action and not from their doctors.

Emotion Among Daughters

Confrontation with their own DES past releases many emotions in DES daughters. Two types of emotion were found in the survey. First, there is a feeling of anxiety and alarm. It is a combination of fear and anger. Second, there are more specific feelings of fear: fear of cancer, of the examination, and of pregnancy complications.

Knowledge and Fear

We found that women who participated more in DES Action do not have more fear than less informed women. On the contrary: it was found that, as DES daughters work more with DES Action and become more knowledgeable, they are less frightened.

The survey concludes that doctors give better examinations, more information, and more emotional support, to daughters who are knowledgeable about DES. Contacts with DES Action influences the experience and attitudes of DES daughters and the doctor-patient relationship. And, last but not least, the method of trying to improve doctors' attitudes through the patients appears to be effective.

Which is Incompetent, Cervix or Terminology?

by Kristie Mattingly

y doctor gave it to me straight: "Kristie, as you know, you have an incompetent cervix." I thought, "What has it done—failed to show up for a scheduled appointment?" "Furthermore," he said, "your cervical mucus appears to be hostile, which is probably why you've failed to achieve a pregnancy." I pictured my cervical mucus under the microscope—there it was, pushing and shoving, and totally misbehaving. It was no doubt responsible for my failure to achieve; if only I could somehow reprimand it....

But my hostile mucus and incompetent cervix aren't entirely to blame; after all, my faulty uterus and bad eggs are just as guilty. A friend comes to mind who recently suffered her third "habitual abortion" (what a lousy habit!). Her miscarriage was due to another "blighted ovum" (the dictionary calls blight a disease, rust, mildew or

I think that this incompetent and hostile terminology, perpetrated by faulty and poor judgment, has failed to achieve adequate descriptions for infertility conditions

smut—evidently her ovum's been through a lot!).

This prompted me to look up a simple term, "menstruation," in a medical dictionary. It was described as "the discharge of dead tissue" and "failure of conception to occur." Does this mean that menses at age l2 was failure to conceive (my mother would have a fit!)? Why not call it what it is—"the normal uterine cleansing process"?

Talk about negative reinforcement—it's no wonder we often feel like failures after a diagnosis or doctor's appointment. It's enough to cause an hysterical pregnancy! I ran these terms by my surgeon husband, who agreed that this negative phraseology is unparalleled elsewhere in medicine. It's surely no coincidence that the vast majority of these terms apply to female reproduction and infertility, though I recently read an article in a major newspaper stating that "50% of all infertility is the fault of the male" (how dare those men!).

I think that this incompetent and hostile terminology, perpetrated by faulty and poor judgment, has failed to achieve adequate descriptions for infertility conditions, don't you? The experts' vocabularies must be blighted!

RESOLVE National Newsletter Iune 1988





Join DES Action!

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



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□ I would like to start my membership through the **Pledge Program** (\$75/year or more). Total yearly pledge \$______ Enclosed is my first □ quarterly or □ semi-annual payment (choose one).

Names of members at the Friend level and above will be listed in a DES Action publication unless requested otherwise.

☐ Please keep my name anonymous.

I am a: DES Daughter DES Son DES Mother other

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DES Action USA 2845 24th Street San Francisco, CA 94110 (415) 826-5060

letters to the editor

Dear Editor:

Your articles are very good. I think they should stress one thing—the DES daughter has some homework to do before trying to get pregnant. This homework consists of becoming acutely aware of her menstrual cycle and shopping for a competent obstetrician.

Being aware of the cycle helps in two ways. The most obvious being that of successfully becoming pregnant. The second being that ectopic pregnancies usually cause some abnormality in the menstrual cycle. By knowing your cycle very well you will be able to alert your obstetrician

when abnormalities occur.

Once you are pregnant, it is good to have already discussed the possibilities of cerclage and other treatment. You will not have to feel rushed into a decision and you may not even want a second opinion.

A.N. Ohio Dear Editor:

I would be willing to give support by telephone to those on bed rest. I well remember those days when a phone talk with a friend was the highlight of my day. Most public libraries will bring books to those who are home-bound. This service really helped me and you might want to mention it to those on bed rest.

M.S. California

Books recently acquired by DES Action

Medication in Maternity: Infant Exposure and Maternal Information by Brackbill, McManus and Woodward (International Academy for Research in Learning Disabilities Monograph Series), \$8.95.

In Search of Parenthood: Coping with Infertility and High-tech Conception by Judith Lasker and Susan Borg (Beacon Press 1987) \$17.95.

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