

DES ACTION VOICE

A Quarterly Focus on DIETHYLSTILBESTROL Exposure

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Summer 1981

MATERNITY CARE FOR DES DAUGHTERS

A Physician's View

by Barbara McCormick, M.D.

Among the special rewards of the practice of obstetrics is the experience of sharing the birth of a normal, healthy baby with a couple who have experienced infertility, miscarriage, stillbirth or newborn death. In the population of DES exposed individuals, these events, unfortunately, are not uncommon. While the true incidence of reproductive difficulty is still unknown, it appears to be significantly increased for these patients.

A pregnancy following reproductive failure is especially anxiety provoking and difficult for the parents. It is also challenging, but stressful, for the physician. On the one hand, the physician seeks to be calming and reassuring (for after all, the odds are still overwhelmingly in favor of a happy outcome), yet on the other she/he knows that there are increased risks. Otherwise minor complications may take on special significance. Major complications carry the possibility of disaster.

The physician wants to do everything possible to insure a normal birth but she/he wants to avoid the overuse of diagnostic and therapeutic modalities to the point that they become risks in themselves – ironically, the DES problem once again!

An essential of care is the early diagnosis of the pregnancy, documented by careful history and physical examination, and confirmed by laboratory tests. Ultra-sound can and should be used to follow fetal growth and to again confirm the date of expected delivery. However, ultrasound should not be over-used, even though there is no significant known risk to mother or fetus. It is very tempting to do this since both parents and doctor like the reassurance of seeing a normal appearing fetus growing well. Also, ultrasound is helpful in localizing the placenta, and now even can demonstrate uterine anomalies, fetal changes in position, cord problems and fetal malformations of a subtle nature.

As the milestones of first audible fetal heart beat, first perception of movement, and the risk of miscarriage and second trimester pass, confidence and closeness between the couple and the doctor increases. The threat of premature rupture of the membranes and of pre-term labor lingers until close to due date. The fear of sudden fetal death is present until the actual delivery of the child. Even the first few days

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The Patient's Experience

by Barbara Yarsin/N.J.

It's a girl! As I heard these three most beautiful words, I thought of the road we had all travelled to get to this precious moment.

My previous pregnancy had proceeded normally and, although I was a DES daughter, no special treatment seemed necessary. Unfortunately, in my 8th month I gave birth to a stillborn girl with the cord wrapped around her neck. The doctors felt it was an accident, most likely having nothing to do with DES. So after three months of grieving, we were ready to try again. Each month passed and my period came. We wondered if I would conceive again.

I went back to work hoping to relieve my anxiety. Finally, after eight months, I missed a period and started feeling the familiar sensations of pregnancy. My obstetrician confirmed our joyful suspicions. She spoke of monitoring this pregnancy more closely, of checking the size of my uterus and the baby's position frequently, through ultrasound.

That evening, as I was telling my friend the news, I began to bleed. We rushed to the doctor, bringing some of the fluid I had lost. She scheduled me for an ultrasound and the fluid was sent to the lab for analysis. The ultrasound was fascinating and yet we were sick with the anticipation of what they would find. I lay still as they passed a wand across my abdomen which picked up sound waves and created a picture of what was happening inside. We saw a small fetus and right on the screen the faintest of heart beats! Our baby was alive! Bed rest was prescribed and for the next four months, I mostly stayed off my feet. (Ironically, had it been 1950, when I was born, I would probably have been prescribed DES.)

We visited the doctor every week and ultrasound

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DES Action groups in action . . .

WASHINGTON, D.C. continues its project as funded by the Meyer Foundation. They have recently completed their physicians survey, (OB-GYNS, as well as Urologists) in Fairfax and Prince Georges Counties. On May 13th, the Maryland State legislature passed House Bill 180, which will promote and maintain a public information campaign on DES, expand existing cancer screening programs, and establish a training program for instructing physicians and nurses in detection, diagnosis, treatment and prevention for DES-exposed persons.

MASSACHUSETTS has been involved in a media campaign reaching nearly two dozen radio, TV and newspaper outlets. They had a successful May meeting and invite anyone wishing to attend future events to contact them. Mass. Senate Bill #651 has been resubmitted. Voice your support.

SAN FRANCISCO hosted representatives from local DES Action groups throughout California. Participants reported their experiences about starting local DES Action groups. The San Diego chapter has found a space for meetings and for mail with an organization called Community Congress. The Los Angeles chapter held its second meeting on March 29th. The Riverside chapter has had a well attended meeting and a lot of publicity. Meetings are now continuing with people who volunteered to help with organizational work. California bill SB1392, passed last year, provides for designating screening centers throughout the state. DES Action/San Francisco has been awarded the contract to do public outreach and the media campaign for this law.

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GREAT LAKES is working closely with the Duluth Community Health Center which will open a screening center in September. The group spoke to UMD Medical School students about DES. This presentation will become required material for all medical students in the future.

TWIN CITIES: a bill prohibiting insurance companies from discriminating against DES exposed or raising their rates, was passed in the Senate and is awaiting vote in the house.

LANSING, MICHIGAN provided in-service training for Muskegon chapter of Michigan Nurses Association and has participated in several Health Fairs.

NEW JERSEY is now providing counseling for daughters at Bergen Pines Outpatient Department. The April 11th meeting, with speakers Drs. Neuwalder, Levine Berdini and Joyce Bichler was a huge success. The N. J. DES Bill S1179 is before the Assembly again.

OREGON and the Women's Studies Certificate Program at Portland State University co-sponsored a public slide show meeting. They also distributed information at a Portland Family Fair.

New Groups Organizing

Local DES Action groups are being formed in the following areas. They will be holding informative meetings and rap groups. If you are interested contact:

Wisconsin: Cynthia Orenberg, 3001 Grandview Blvd., Madison, Wisconsin 53713.

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DES DAUGHTER

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A True
Story of
Tragedy
and Triumph

THE
JOYCE
BICHLER
STORY

BY JOYCE BICHLER

In a landmark legal battle,
she fought a major drug company—and won.



THE JOYCE BICHLER STORY

Joyce Bichler was only eighteen when doctors discovered she had a rare form of cancer, and she was forced to undergo a hysterectomy and vaginectomy to fight it. Seven years later, in 1979, she faced the Eli Lilly Drug Company in the New York State Supreme Court, winning over half a million dollars in a landmark battle – for damages caused by the drug DES (Diethylstilbestrol), given to Joyce's mother, and millions of other women, during their pregnancies.

No DES daughter or son had ever won such a suit, but Joyce Bichler was determined, in her agony and fury, to

bring the pharmaceutical company to justice. Supported by her family and her boyfriend who later became her husband, she contested that DES had not been adequately tested before its widespread use, and that it was not even effective for what it was intended – preventing miscarriages. *DES Daughter* is the first account of the DES controversy to be written by the victim herself. It is a story of courage and personal struggle, of outrage over the cancer that never should have happened, and of the exhilarating, groundbreaking victory against a company that went to great lengths to defend itself.

Joyce's book is published by AVON Books, 959 Eighth Avenue, New York, NY 10019, and is available from your local bookstore or from DES Action, 1638-B Haight Street, San Francisco, CA 94117.

Warning on Cryosurgery Continued

Kris Brown / San Francisco

Several months ago, the *Voice* issued a warning on cryosurgery, a freezing technique used to treat abnormal cells on the cervix (dysplasia). We noted that conversations and correspondence with DES daughters indicated to us at DES Action that cryosurgery is a common treatment for dysplasia. We also called attention to the opinion of Dr. Wesley Fowler, Director of the Department of Gynecologic Oncology at the University of North Carolina. In his correspondence with DES Action and in published studies concerning cryosurgery, Dr. Fowler has emphasized the need for caution when treating DES daughters.

To understand better what the risks and choices are for a DES daughter with dysplasia, I took a closer look at Dr. Fowler's studies, defined some of the medical terms and procedures that were confusing to me, and, with the help of two doctors, developed some guidelines that a DES daughter with dysplasia can use in discussing with her doctor the best treatment in her own case.

First, some definitions:

Dysplasia refers to a condition of abnormal cells usually on the cervix. Dysplasia should not be confused with adenosis, which is the abnormal

presence of glandular cells in the vagina (it is normal for glandular cells to be present in other parts of the body; not in the vagina). Adenosis is very common among DES daughters and not at all common among non-DES daughters. Cervical dysplasia is found in both DES and non-DES daughters; however, the incidence may be higher among DES daughters.¹ Nowadays, doctors are replacing the term dysplasia with the term CIN (*cervical intraepithelial neoplasia*), which means essentially the same thing: abnormal cells. CIN is classified as CIN I, II, III, depending on the severity and extent of the abnormal cells. Instead of using the terms mild, moderate and severe dysplasia, as before, physicians now talk about CIN I, II, and III, which roughly correlate to the previous dysplasia terms. One difference is that CIN III also includes *carcinoma in situ* (CIS), a non-malignant, non-invasive, usually slow growing, but in many cases, pre-cancerous condition of the cervix. *Invasive Squamous Cell Carcinoma* refers to cancer, and it is sometimes hard for pathologists to distinguish it from CIS.

Cryosurgery is a technique of freezing the tissue that is affected with dysplasia (CIN). A probe is placed on the affected area and the area is frozen

rapidly, then allowed to thaw, and usually frozen again. In many cases more than one treatment is necessary to destroy all the affected cells. According to many doctors, the advantages of cryosurgery (compared, for example, to conization), are that freezing "destroys the nerves so rapidly and the vascular channels are sealed so promptly that pain, blood loss, and infection are reduced to a minimum."² It can also be done in a doctor's office and requires no anesthesia. It is necessary to have continuing and regular follow-up exams after cryosurgery in order to check for changes and a recurrence of abnormal cells.

Conization, or cone biopsy, involves taking a cone-shaped portion of tissue from the cervix. It can go deeper into the tissue than cryosurgery and is used when the full extent of the abnormal cells cannot be seen during the colposcopic exam. It usually requires hospitalization and anesthesia. Conization may also carry the risk of cervical stenosis.

Hot cauterization, or hot cautery, involves burning rather than freezing the cells. Cryosurgery has replaced this procedure in most cases.

Cervical stenosis is a narrowing of the cervical canal, often so much that as a result a woman will have painful periods, or may even have trouble dilating during labor. Cervical stenosis is caused by scar tissue which can develop as a result of infection, or following cryosurgery, conization, or

Cryosurgery continued

cauterization. Cervical stenosis is sometimes successfully treated by applying a dilator to the affected area.

The studies:

One study by Dr. Fowler and his colleagues (Drs. Schmidt, Talbert, and Edelman, Ph.D.) is titled "Reproductive History of Women Exposed to Diethylstilbestrol in Utero." Their main finding in regard to cryosurgery is that 75% of DES daughters suffer cervical stenosis from this procedure, compared to less than 1% of the non-DES daughters.

Cryosurgery, regardless of indication, leads to significant cervical stenosis in three of four DES-exposed women treated. Eight of these (39) women required operative intervention to relieve severe dysmenorrhea [painful periods]. As a comparison, in the University of North Carolina dysplasia clinic, less than 1% of all cryosurgical procedures have led to comparable cervical stenosis. Considering the known DES-related uterine (and presumably cervical) structural abnormalities and reproductive problems reported here, it seems highly inadvisable to subject a DES-exposed female to cryosurgery. However, we have found that in selected cases, use of cryosurgery to focal areas successfully avoids problems with cervical stenosis.³ [Emphasis added.]

The study raises important questions: Why do DES daughters get cervical stenosis when non-DES daughters do not? If cryosurgery is inadvisable for DES daughters, what are the other choices? Is delaying treatment a choice?

Fowler and Schmidt addressed some of these questions in a more recent article, "Cervical Stenosis Following Minor Gynecological Procedures on DES-Exposed Women," published in *Obstetrics & Gynecology*, September 1980. They offer the following explanation for why DES daughters are affected more than non-DES daughters:

The DES-related structural abnormalities in both the cervix and uterus may well be associated with connective tissue alterations that predispose to abnormal healing. The smaller diameter of the endocervical canal... may also contribute to the increased propensity to cervical stenosis. These findings also suggest caution, at least on a theoretical basis, in the use of intrauterine devices in these women.

They recommend caution in treating DES daughters:

Operations on the cervix and probably on the uterus in DES-exposed women must be approached cautiously. Excision, cryocautery (cryosurgery) or electrocautery of cervical structural abnormalities or on areas of adenosis as recommended by some authors, cannot be condoned.

And in conclusion they warn:

Our main point at this time is that until many of the issues that are currently under investigation are answered... there should be very strong indications for any procedures performed on the cervix other than diagnostic procedures.⁴

The question left unanswered is what a DES daughter with dysplasia should do. I found that most research on the treatment of dysplasia is based on non-DES daughters. Indeed, there is no consensus on treatment of DES daughters at this time. The guidelines I have developed are based on the above DES studies, other studies that are not specific to DES, and on conversations with doctors who are experienced with DES-exposed and with cryosurgery.

Guidelines for DES daughters with a diagnosis of dysplasia.

Diagnosis:

Make sure the diagnosis is accurate. Have a complete exam, including, in the opinion of many doctors, a colposcopic exam and punch biopsy or biopsies. A punch biopsy is the clipping off of an abnormal area that can be seen through the colposcope during the exam. (The colposcope is an optical device that works like a magnifying glass.) Each biopsy is about the size of a half grain of rice, and it is sent to a pathologist for analysis. The biopsy is especially necessary for DES daughters because adenosis, a benign condition common among DES daughters, can be misdiagnosed as dysplasia ("healed" adenosis may look like dysplasia). It is necessary to have a punch biopsy and pathological reports to make the distinction. Some doctors may also recommend that a smear be taken from inside of the cervical canal (called an endocervical curettage or ECC). Other doctors include an iodine stain (Lugol's or Schiller's stain) which is applied to the cervix and vagina. Abnormal areas usually do not stain, normal areas usually do. I emphasize "usually" because false tests have been reported.

Treatments:

For CIN I (mild dysplasia) many doctors recommend that DES daughters simply return in 3-6 months for another complete exam; no treatment is done until then. If you know you cannot return in 6 months, then the doctor may recommend cryosurgery at the first diagnosis.

For CIN II, many doctors recommend cryosurgery if they can see the full extent of the abnormal cells during the colposcopic exam. If cryosurgery is recommended, it is especially important for DES daughters to discuss with their doctors whether limited cryosurgery only to focal areas may – as pointed out in the study – avoid problems. If they cannot see the full extent of the abnormal cells, they will probably recommend a cone biopsy (conization).

For CIN III which includes carcinoma in situ (CIS), many doctors will recommend conization or a hysterectomy, depending on

the extent of the abnormal cells. Certainly a recommendation of hysterectomy would require a second opinion. A second opinion would also be appropriate for less radical procedures such as cryosurgery or conization. You should know that not all CIS eventually becomes invasive cancer.⁵ Cryosurgery is used less frequently for CIN III than for CIN I or II. According to one study by Donald Ostergard, M.D., "39% of the patients with CIN III demonstrated persistence of lesion after cryosurgery," compared to 6.2% for those patients with CIN I and II lesions.⁶

Summary:

DES daughters with dysplasia face a difficult decision when cryosurgery or other techniques are recommended for treatment. We do not know why DES daughters are more likely to get cervical stenosis from cryosurgery, and other treatments (cauterization, conization) may not have better results and often require hospitalization and anesthesia. There is a new treatment for dysplasia, laser treatment, currently in use by some medical professionals, but it is still controversial. In light of the information presented here, you may want to discuss with your doctor the possibility of not treating the dysplasia immediately but waiting in combination with coming for frequent exams to check for any changes of the abnormal cells.

In general, based on the information available now, the most important guidelines for DES daughters are:

1. Find a team of doctors who have experience with both DES and non-DES daughters. Only an experienced clinician and pathologist can make an accurate diagnosis. To quote one text: "In view of the wide variety of cellular patterns and the frequency of both benign and malignant cervical diseases, these alterations (CIN) present major challenges to the pathologist."⁷ And the advice from the study recommending "use of cryosurgery to focal areas" can be useful only to an experienced cryosurgeon.

2. Always consider seeking a second opinion.

3. Know as much as possible about your particular condition (DES Action collects a lot of the medical papers, and studies are also available at hospital and university libraries). Find a doctor with whom you can discuss the possible causes of and treatments for your condition.

4. Remember that check-up exams after treatment or continuing check-ups if no treatment is done are very important.

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HANDLING A 12 YEAR OLD'S FIRST EXAM

I have four children. My two sons and my twelve year old daughter are DES exposed. I first found out about DES causing problems when my daughter was two years old and have spent all these years worrying and anticipating her first exam and her future. Everytime I read a newspaper article about DES, I became more frightened. The media made it seem that cancer was inevitably in her future. I couldn't deal with it and I buried facing the issue.

My husband thought I was overreacting. I had heard about DES Action but did not want to make contact with the group. If I didn't talk about it, I could pretend the issue didn't exist.

Just before her 12th birthday, Christine came to me with a blood spot on her panties. I couldn't hide anymore. I told her it was probably her period, but she did not want to talk about it. It embarrassed her. I called my gynecologist, who does DES examinations, and asked for advice on how to handle it. When he wanted to set up an appointment immediately, I really became frightened. How could I tell Christine?

She was so modest and very concerned about her health. I was afraid the exam would change her, cause her to dwell upon her body, make her lose the carefreeness of childhood. I was afraid of what the doctor might find.

I knew I had to tell her because the appointment was set. I could not think about it without crying. I found I was unable to handle my everyday activities. I needed help. My husband suggested now was the time to call DES Action.

The volunteer who answered the phone told me not to speak with Christine until I was calmer and more in control of myself. She also recommended that I consider taking Christine to a female gynecologist since she was so modest, and that we both read the book *Period* (See Vol. 1, No. 4) as it emphasizes the importance of preventive health care and internal exams for all girls once they've begun to menstruate. This would make the exam for my 12 year old seem more "normal".

It was a lucky coincidence that the next evening a meeting for the parents

of young DES daughters was scheduled. I attended with my husband and was encouraged by the nurse's discussion of the cancer statistics and how small the risk of cancer actually is for DES daughters. I was reassured to learn how many young girls had coped positively with their first exam and considered it a normal part of growing up. After listening to the other parents, I found that my fears and apprehensions were not unique. I wished that another family who had already faced the first exam was there to give advice. That's the reason I wanted to contribute this to the Voice: to share our experiences.

After the meeting, (before talking to Christine) I made the appointment with a female gynecologist. I was so eager to have the doctor see Christine. I know now that it would have been better to have told my daughter about her DES exposure first and let her choose the date for her examination. As it was, the date was sprung on her and we had to change it to one she wanted.

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THE REDBOOK ARTICLE: THE AUTHOR'S REACTIONS

Last summer, I took a deep breath and sent an article I had written to *Redbook* magazine. The article concerned a part of my life that had always remained private and painful – the absence of a menstrual cycle and my infertility. I told of my experiences with doctors who kept telling me these problems were likely emotional. I described my contacting DES Action after experiencing the loss of a baby in the sixth month of pregnancy, conceived after treatment for infertility. The loss was caused by an "incompetent cervix" resulting from my DES exposure.

I knew why I had written the article. Other women must be in similar situations. They needed to know what I had learned through volunteering with DES Action, about the range of reproductive tract abnormalities now associated with DES exposure (e.g., evidence of menstrual, fertility and pregnancy problems, as well as the rare clear-cell adenocarcinoma). They needed to realize how crucial it is to receive medical care from health professionals trained and up-to-date on

problems of DES exposure. I am convinced that only when women begin to share private and often painful health experiences, and then work together in informing and supporting each other, will we ever begin to gain control over our own health and well-being. In the case of a magazine article, I assumed the communication would be one way.

DES Action received
over 1500 inquiries,
and I personally
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and phone calls.

I was wrong. DES Action received over 1500 inquiries, and I personally received many letters and phone calls. I was frankly amazed by the numbers of women in all parts of the country who needed and wanted to make contact. The response served as a reminder of the work to be done. Many who did contact us were hearing about DES for the first time; they

were just now making the connection, asking, "Could a drug my mother took while pregnant with me be the reason for . . .?" Others already knew they were DES exposed, but had no access to information about the health care they needed. They were eager for the latest findings on DES effects, asking us to "send whatever information you have." In many parts of the country, the problem was access to doctors trained in DES care. Women wrote that their local doctors did not know about DES or said it was no problem, or recommended questionable procedures. "Can you tell me the closest place to my home where I can get a DES exam from someone who really knows?" they asked. I realized that those of us who do have information, who do keep in touch with DES Action need to be reminded now and then of how many people have not yet been reached.

I could not help feeling, at times, overwhelmed and saddened by the response. We heard, repeatedly, how DES has affected, and in many cases

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PHYSICIAN'S VIEW

Continued from Page 1.

of life are more anxious and stressful for these new parents.

Throughout the pregnancy, attention is paid to excellent nutrition, proper balance of exercise and rest, avoidance of environmental hazards (practically impossible these days). In late pregnancy, the fetus is monitored by estriol determinations – a hormone test on 24 hour urine collections, which show that fetal and placental function are normal, and by non-stress testing – monitored fetal activity and heart rate patterns in a controlled manner.

The management of actual labor and delivery is generally that of high-risk protocol, including fetal monitoring and being attuned to the effect of possible uterine or cervical malformations, though this is quite rare. Of more concern recently is the possible effect of adenositis treatment and repeated biopsies on the cervix. Again overzealous treatment may be more harmful than no treatment, or watchful waiting.

The management of a DES daughter's pregnancy, especially after a loss, is, then, a combination of very cautious obstetrics, judicious use of diagnostic procedures, common sense measures and lots of reassurance, emotional support and "tender, loving care" of the parents.

PATIENT'S EXPERIENCE

Continued from Page 1.

was done every few weeks to monitor fetal growth and positioning. The bleeding continued. Sometimes I passed clots and each time they were analyzed by the lab. Yet each ultrasound indicated growth. The fetal head size was even measured to monitor development. At first the placenta appeared to be lying low in my uterus, but as time progressed the fetus moved up and assumed a horizontal (transverse) position. It also seemed that my uterus had enough room.

I began to notice movement in the fourth month and suddenly the bleeding stopped. Each day we monitored the kicks to learn their pattern. We were watching for any slowdown or rapid change which might indicate fetal distress. When I entered my eighth month, I went to the hospital every few days to be hooked up to a machine which monitored the fetal heartbeat. Again, they were looking for any inconsistency that might indicate that the baby was in stress. Additionally, every few days I collected 24 hours of urine. Then estriol counts were done to see if the placenta was still functioning properly – nourishing the fetus and eliminating waste. Each afternoon I waited nervously for the count to come in. Had it dropped below a certain level, they would have taken me right in and performed a caesarian section.

The baby dropped and was in a head-down position, and I began dilating at the beginning of my eighth month. One day during a routine checkup, the doctor no

longer felt the baby's head, indicating its position had changed again. We were so anxious and scared that the baby would somehow become entangled in the cord like the last time. A decision was made to go ahead and have a caesarian the next day. We arrived at the hospital and I was prepped. As I lay in the labor room, my doctor examined me and said that the baby had dropped back down into position. She decided to break my water to induce labor. The induction worked. I began dilating and ten hours later I was dilated ten centimeters and I started pushing.

Rebecca Leigh was born!

Her birth announcement read "All things are possible to he who believes". I believe and so must we all. With the expert medical care I received and the constant support of my husband and family, our dreams came true.

FIRST EXAM

Continued from Page 5.

I did a lot of thinking after the meeting, calmed myself down – I was ready. Christine was studying the female body and reproduction in her health class and I used this to broach the subject. In a matter of fact tone I spoke about my previous miscarriage and that I took DES while pregnant with her and that was why she would have to go for an exam. We read *Period* together. I was so relieved. It was out in the open. She seemed to handle the prospect of the exam well, but didn't ask many questions and went off to play with her friends. Our discussion did not disrupt her daily activities. I became concerned that because she did not question me, she did not understand everything I had told her.

We planned a special day around the exam. We shopped, went to lunch, on to the exam and then we shopped again. On the way to the doctor's office, she said, "I just want this to be over – I'm not afraid of the exam. I just don't want her to find anything wrong with me." That's when I knew that she did understand all that I had told her and her daily actions showed me she was really coping well.

I was with Christine during the exam. During the colposcopy portion, I felt faint and left the room. By the time I returned she was dressed and ready to leave. The nurse said, "You did beautifully, Chris! Next time leave your mother home." The doctor told us that there might be normal staining even if her period did not begin for some time. She wanted to see Christine again in six months.

After we returned home, Christine headed for the phone and made plans to go rollerskating. The fears that I had that the exam would change her were groundless. I, however have noticed changes in myself since the DES parents' meeting. I always had difficulty in discussing topics of a personal nature with my children. Now I want them to feel free to speak to me about anything that is on their mind. Our DES

exposure has created a bond of closeness between us that did not exist before. I realize that in the future, I will have to deal with my sons and their exposure. I feel I will be better equipped to handle the situation.

REDBOOK ARTICLE

Continued from Page 5.

drastically altered, people's lives in ways the statistics will never convey. We heard from women all over the country whose lives have been too filled with doctors, hospitals, fears, pain, and illness. But at other times, I felt some solace, in that at least their feelings of isolation were broken and they were not alone. Some women's stories were uncannily close to mine.

I sensed some relief in the letters and my reaction to them – at hearing of another person who knows something of what you have been through. "I would love to talk with other DES daughters (or mothers) who live near me," women wrote.

I especially felt the urgency of connecting all of us, of continuing to reach out to make sure women and men find out if they are DES exposed and to educate them about the health care they need. If this many people responded to an article in *Redbook* (Feb. 1981), how many women and men are out there – particularly in areas where DES Action is not yet active – who still do not know they are exposed, or have no one to talk with, no one who can give them any answers?

Clearly, our job of outreach and education to the public and medical profession is far from over. We need to keep DES exposed individuals knowledgeable and demanding, and to continue helping health care providers stay up-to-date. We must make certain that research progresses on the effects of DES exposure and the best ways to avoid further DES-related injury.

The response to the *Redbook* article confirmed to me that it is up to us, the exposed. You could say we have a jump on those untouched by the DES experience. We have been taught, the hard way, a lesson all people, DES exposed or not, would be well-advised to learn: that if individual women and men, working together, do not keep on top of their own health care, seek out, inform and support each other, put pressure on the medical profession, drug companies and legislators, no one else will.

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Continued from Page 4

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LETTERS TO THE EDITOR

Dear Editor,

I am interested in hearing from anyone who had previously been unable to conceive because of DES-related anatomical abnormalities and has now achieved a successful pregnancy and birth. I am especially interested in knowing what course of treatment, if any, has been followed in order to achieve a pregnancy. I am a DES daughter with cervical adenosis, shortened endo-cervical canal and infantile uterus who has been unable to conceive and has been told by a number of physicians that there is no known course of treatment available.

Sincerely,
Linda J. Cain

Please send responses to: Linda Cain, c/o The Voice.

DES and Science Medical Abstracts

by Carol Simpson/Washington, D.C.

- "Delayed Onset of Clear Cell Adenocarcinoma of the Vagina in DES-exposed Progeny"; N. Veridiano, et al. *Obstetrics and Gynecology* 57 (3) 395-8; March, 1981.

Fortunately, the development of cancer in a DES daughter who has been followed only for adenosis is extremely rare; this paper describes the second reported case. A 24-year-old female was seen for four years before developing a nodule, which, at biopsy, showed only adenosis. At her next examination, ten months later, she presented with a larger nodule, and this revealed adenocarcinoma. Her surgery was essentially uncomplicated and at the time this article was written, she was doing well. One important finding is that her nodule was *palpated*, not seen, indicating the need for palpation as well as other diagnostic techniques. The authors also suggest that the development of a malignancy in a patient with adenosis indicates more than ever the necessity "for careful regular follow-up using cytology, digital palpation, and colposcopy at 6-month intervals".

- "Upper Genital Tract Changes and Pregnancy Outcome in Offspring Exposed in Utero to Diethylstilbestrol", Kaufman, R.H., Adam, E., Binder, G.L. and Gerthoffer, E. *Am. J. Obstet. Gynecol.* 137:299, 1980.

Dr. Raymond Kaufman and his colleagues at Baylor College of Medicine have written yet another article sadly confirming the high incidence of fertility problems in DES-exposed daughters. Two-hundred-and-sixty-seven daughters and 87 non-exposed women, all from the DESAD project, were studied. Sixty-nine percent of the DES-exposed women demonstrated uterine abnormalities on hysterosalpingogram (HSG); 44% had structural changes in the cervix. An interesting finding was that in women with vaginal epithelial changes (gross changes of adenosis, non-staining squamous epithelium, etc.), abnormal HSG was much more common than in DES daughters without these vaginal findings (82% vs. 44%). In those DES daughters who had been pregnant (93), only 58% of the births were live, normal deliveries, compared with 87% of the pregnancies in the non-exposed control group.

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