## V O I C E

A FOCUS ON DIETHYLSTILBESTROL

Winter 1995

#63

# Childless or Childfree\*: Decision Making for a Lifetime

By Kari Christianson and Amanda Sherman

American couples, pregnancy does not simply "happen." Infertility strikes millions of men and women every year in the United States, and the numbers are growing. The good news is that today's medical technology has much to offer those who suffer from infertility. The bad news is that there is no guarantee that you will come home with a baby of your own.

Never mind the costs—expensive in every sense (physically, emotionally and financially). Forget the frequency of success—statistics from an unregulated industry are confusing at best. The fact remains, that women are being given fertility drugs in record numbers. And who knows what price they may have to pay when the long-term effects of these drugs are finally assessed? A familiar story for the

Third
Generation
Survey
p.3 & 4

"And who knows what price they may have to pay when the long-term effects of these drugs are finally assessed? A familiar story for the DES exposed!"

DES exposed!

If infertility treatments sound grueling, try putting closure on the dream for a biological child when nature or technology fails. And what infertile person does not cherish the hope for a biological child, at least for awhile? With so much at stake, it's not easy to know when to get off the infertility roller coaster, especially when we live in a culture where even Arnold Schwartzenegger manages to achieve pregnancy through a medical miracle and the magic of the silver screen ("Nothing is inconceivable").

But what about the relatively small percentage of infertile couples who have found their way to live a happy and meaningful life without children? How did they get to this point? And, with so much attention focused on the options for those struggling with infertility, why has the choice NOT to have children remained in the shadows for so long? While there are numerous books and dozens of resources to guide people through the maze of medical treatments or the rigors of adoption, little help is available for those who wish to explore the idea of a childfree lifestyle—a subject which demands no less special consideration, even if it is "the road less traveled."

Obviously, there are enormous societal and cultural forces at work leading to the path of parenthood. It is easy to see how the pervasive ideal of "parenthood for all" places great stress on anyone who even ponders the idea of a childfree lifestyle. When the issue of infertility is added to such deliberations, the situation can become especially painful. For example, women who are diagnosed as "infertile" still run the risk of being referred to as "barren"—a term which also

continued on page 7

<sup>\*</sup> The term "childfree" is not a popular term, but rather a term which attempts to redefine the prevailing sense of loss and diminishment associated with the word "childless."

#### VOICE

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Each group was created and nurtured by volunteers. Write them if you want information on their activities or can volunteer.

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#### Our "Third Generation"

ver the years, DES Action has received many inquiries asking if a particular health problem in the children of DES daughters and sons might be related to DES exposure. Our answer must be, "No one knows." We do know that many conditions are probably not related to DES exposure. With so many people exposed, we expect to see the usual range of physical and psychological problems that appear among the general population. At the same time, these 'anecdotal' reports do concern us, particularly when they begin to sound repetitive.

DES Action is now taking steps to help identify whether certain health conditions appear more frequently among the offspring of DES daughters and sons—the "third generation" than among non-exposed people. We want to document and count the stories. The Health History questionnaire on page 3 and 4 is an important first step. The survey is informal. It is not intended to be a scientific study. Your responses will provide a crucial "first look." If any trends are suggested by the answers we receive, we will discuss this information with scientists who can follow up with further studies.

We have listed a large number of possible conditions. We encourage you to add others you have observed. Remember, most have **not** been associated with DES exposure, and we are **not** suggesting that they are related. Do not send the questionnaire to us: mail it to our researcher, Dr. Wingard, whose address is at the end of the form.

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### "Third Generation" Health History Questionnaire

DES ACTION wishes to compile information on the health experiences of the children of women and men exposed to DES in utero (children of DES daughters and DES sons; DES grandchildren). We do not know if this "third generation" has special health problems, as no research has yet been done. However, collecting clues in this way can help us alert the scientific community to possible areas of needed research.

If you are a DES daughter or DES son who has biological children, we hope you will help us by filling out the following questionnaire. If you are a woman who took DES during pregnancy (a DES mother), please pass a copy of this questionnaire on to each of your DES exposed children. Thank you.

Are you a DES-exposed:	Know for sure	Think I am		
Mother				
		$\overline{\Box}$		
Daughter	님			
Son				
Have you ever tried to obtain me	dical records to verify D	ES exposure?	Did you receive th	e records?
Date of your birth				
If you are a DES daughter or son	how many biological o	hildren do vou have?	daughters	sons
How many of these children were			daughters	sons
now many of these children were	bom prematurely (belo	ie tile 37th week)!	LILI daugniers	SUIS
Please list their date(s) of birth:		Daughter(s)		Son(s)
	1	/ /	1	111
	2		2	1 1
	3.	1 1	3	
	4		4	
	5	1 1	5	1 1
If any of your biological children have two sons with asthma, put a	"2" in front of asthma u		Se list the number of each  Number of your son	
Number of your dau Allergies	giners		Allergies	9
Allergies mild			mild	
moderate			moderate	
severe			severe	
Asthma	C	F	Asthma	,
Arthritis			Arthritis	
Cerebral palsy			Cerebral palsy	
Developmental dela		Developmental delays:		
describe:		describe:		
Diabetes		Diabetes		
Early puberty: age:			Early puberty: age:	

VOICE

Number of your daughters	Number of your sons
Adenosis Cervical anomalies (collar, ridge, hood) Menstrual problems:	Undescended testicle Epididymal cysts (benign tumors on testicles) Testicular cancer Other cancer:
Dysplasia (CIN) Carcinoma in situ: where?	Citici dancer.
Clear cell cancer: vagina or cervix  Other cancer of vagina or cervix:	
Breast cancer Other cancer:	
OTHER conditions:	<del>ままっ</del> 。 List Microsoft Wiking Microsoft State
and the second of the second	No. 2 Supering and the subject to the
Has a physician ever said your child's illness/health cond  If YES, please describe:  Do you know of any other biological children of DES da  If YES, please describe:	nughters or sons with unusual problems?
	ry):
Adding your name and address is optional:	Please return this questionnaire to:
Name	
Address	DES Action Research Consultant

## **Questions and Answers**

r. Kenneth Noller was one of the featured speakers at our October meeting in Massachusetts. He has worked for years on the DESAD project, following the health history of over 3,000 DES daughters, and is now directing one of the five collaborative studies funded by our 1992 legislation.

After his historical overview—in which he reminded us that as early as 1941 the Journal of the American Medical Association warned of the possible carcinogenic effects of DES—Dr. Noller summarized the current knowledge. A recurring theme was the need for more research, as is shown in his reply to these questions.

#### Q: Is bed rest effective in slowing pre-term labor?

A: There is no data to support this. We do it, but we don't know if it works. It may help.

## Q: Can a woman with a uterus one-third normal size carry to term?

A: A small uterus is a real problem. We have seen cases where stretching seems to occur and eventually the woman will have a term delivery.

## Q: What about third generation effects, alteration in the genes? A: We have no idea.

## Q: Do DES daughters have an increased risk for HPV (human papilloma virus)?

A: About one-third of young people under 35, male and female, have HPV, whether or not they were DES exposed.

Many people do not know they

have it. I will say, you won't get squamous cancer of the cervix unless you've had HPV.

#### Q: Is there a link between DES exposure and endometriosis? A: Information we have comes from self-selected groups, or selfreporting. We have no good study on this. The DESexposed in our

DESAD study had fewer cases than the controls.

### Q: Will DES daughters have an earlier menopause?

A: That has not shown up in our studies.

### Q: How often is colposcopy necessary?

A: If there have been no vaginal changes, colposcopy is not needed. For daughters with adenosis, every year.

## Q: Percentage of daughters with incompetent cervix? A: This condition is not terribly

common.

Q: Hormone replacement treatment for DES daughters?
A: We don't know. DES daughters are just getting to the

daughters are just getting to the age of menopause. It makes sense that a woman who is DES exposed shouldn't be exposed to more estrogen. On the other hand, that is a theoretic thing. We don't know for sure that it is bad and we do know there are defi-



At our October meeting we presented Dr. Kenneth Noller with a plaque in appreciation for his services to DES daughters in his years of research and clinical practice. Pictured above, left to right, DES Action President Karen Fernandes, Dr. Noller, DES Action Treasurer Kari Christianson.

nite medical benefits for women: osteoporosis and heart disease. Proven benefits. Should we say "Don't take estrogen?" We don't know.

## Q: After hysterectomy, how often should a DES daughter get checked?

A: She should have an annual Pap test of the vaginal wall.

## Q: Is it safe to be on the pill? Is there a time limit for safety?

A: In our study, we saw no problems. No age limitation for non-smokers.

## Q: Evidence of thyroid cancer in DES daughters?

A: No. That is a common cancer. We need to be careful not to attribute everything to DES.

#### Q: Does dysplasia recur?

A: Serious dysplasia, once removed, doesn't tend to come back.

### V O I C E

### letters to the editor

Dear Editor:

I really appreciated the article "Personal Story" by Sandy Prantl in the Fall 1994 newsletter and have a similar account to share that might be of interest to your readers.

My husband and I struggled with infertility for nearly four years. When I went off birth control pills a few years into our marriage, and several months passed without having a period, I sought the services of an ob/gyn. Because I had always had irregular periods, and because I had been underweight and a late starter (age 19), the doctor saw no reason for concern until a year had passed without periods. (We did not know I was a DES daughter). After a year, when blood tests indicated all was normal but that my thyroid hormone was in the low normal range, she put me on a low dose of synthroid (a synthetic thyroid hormone) and my periods began.

Shortly after that time, I moved out of state. Because I had never been told to renew my prescription for synthroid, I simply stopped taking it when the pills ran out. My periods continued, irregularly, but we did not get pregnant. I saw a new ob/gyn and discovered I was not ovulating. For several months I was put on Clomid, but the doctor never mentioned renewing my thyroid medication. Finally, I was referred to an infertility specialist who conducted several aggressive and expensive in-utero inseminations while continuing the Clomid treatments, but when asked about my thyroid problem, he said that because my blood

levels were normal (indicated by new tests), I did not need thyroid therapy.

Again we moved out of state. A new infertility specialist spent months focusing his efforts only on the possibility of a mycoplasma problem, then finally conducted some blood tests and a hysterosalpingogram. During this X-ray, we discovered that I had a T-shaped uterus, possibly caused by in-utero exposure to DES. (My mother felt certain she did not take DES, and my doctor indicated that environmental factors could also cause a Tshaped uterus, so I wanted to believe I was not a DES daughter). The doctor also decided to put me on synthroid after several months of other treatments since my blood levels of thyroid hormone were, again, in the low normal range. If I truly needed thyroid hormone, he explained, I would be on it the rest of my life, and could not support a pregnancy without it. This was a revelation to me. Had my husband and I been wasting our time and money all of these years?

Only a few months after beginning the thyroid therapy, and much to our astonishment, I became pregnant for the first time, and am now doing well in my fourth month. Because my husband and I had experienced an array of problems and treatments, we weren't sure why we were now pregnant, but Sandy Prantl's story led me to believe the thyroid hormone was critical. It also told me that my slight Hypothyroidism probably indicated that I was, indeed, a DES daughter. How many other

couples have been wasting their time and money on expensive infertility treatments because this simple hormone deficiency was not diagnosed? How many other infertile DES daughters do not know to look for this possible subtle contributing factor?

The problem of subtle hypothyroidism in infertility deserves more scrutiny by the medical community. Thanks again to Sandy Prantl for pointing this out.

Kari Norborg Carter Centerville, OH

I'm writing to follow up on my story in the Fall issue of the Voice. I thought that it may be helpful to provide the references of where I learned about hypothyroidism and its relationship to infertility. Readers may then investigate for themselves and determine if this information applies to their circumstances.

- 1. Diamond, Kathleen, Mother-hood after Miscarriage. Chapter 10, Luteal phase deficiency, a nongenetic cause of miscarriage, published by Bob Adams Inc., 260 Center St., Holbrook MA 02343.
- **2.** Murray and Pizzorno, Encyclopedia of Natural Medicine, chapter 49, **Hypothyroidism**, published by Prima Publishing, Box 1260 MP, Rocklin CA 95677. (916) 624-5718.
- 3. Balch and Balch, *Prescription* for Nutritional Healing,
  Hypothyroid pp. 213-214,
  published by Avery Publishing
  Group, Garden City Park, NY
  11535.

Sandy Prantl

### Childless or Childfree?...

continued from page 1 means "useless" and equates the significance of womanhood strictly in relation to reproductive capabilities. Because of the powerful cultural expectations placed on motherhood, women in particular must sort out how much of their desire for children comes from societal expectations and how much of their desire, or lack of it, comes from within.

Another common cultural expectation is that if you can't have biological children, you will "just adopt" instead. This almost automatic assumption is a double affront which not only implies that every infertile person wants children, but also manages to offend those who've endured the difficult, often insurmountable, problems associated with adoption. Furthermore, society is also quick to label those who do manage to adjust to life without children as "selfish." And after suffering the sacrifices of infertility, this charge can be especially hard to cope with.

As difficult as it is to challenge the cultural mandates which insist on parenthood, frequently the deepest pain hits home in a literal sense when it comes to family and/or friends. Dealing with gatherings where attention is focused primarily on children, watching siblings or peers raise a family, or coping with the disappointment of parents who are hoping you will provide them with grandchildren, are hard to deal with. The decision to remain childfree is not easily validated, especially in such situations.

So, how does an individual or couple make the decision to

become a parent or not? The answer to that question lies, in part, with the operative word "decision." For, although we all write our life's story by the decisions we make, the power of choice is often strikingly absent in the "decision" not to have children. Frequently, people drift along in a netherworld of infertility for years, holding onto a vague sense of hope. Or maybe they get tired of trying, or run out of funds, or put a "happy face" on a bad situation by telling themselves and others that it doesn't really matter after all. Whatever the reasons, a lack of active decision making is rarely benign. In such cases, feelings of resignation, or a sense of failure, mark one of life's most significant milestones.

Jean and Michael Carter address this issue directly in their insightful book, Sweet Grapes: How to Stop Being Infertile and Start Living Again:

...being infertile is not a medical, legal, or scientific issue. It is a human issue. (It is) about loss and the way people respond to it....

It is possible to move beyond the crisis of infertility and to get on with a meaningful life, even if you don't end up with a child. But in doing so, first the reality and depth of loss must be faced. Putting successful closure on infertility means going through a mourning process and coming out on the other side. And as the experts tell us, there is no short cut when it comes to coping with grief, other than facing loss squarely and letting despair run its course. This route appears to

## For further reading on this subject:

Sweet Grapes: How to Stop Being Infertile and Start Living Again by Jean W. Carter and Michael Carter, 1989. Perspective Press Box 90318 Indianapolis IN 46290-0318.

Women Without Children: the Reasons, the Rewards, and the Regrets by Susan S. Lang

Reconceiving Women by M.S. Ireland Guilford Press, New York

be the most effective and certain way for eventually finding peace. For many, infertility represents their first encounter with a profound sense of grief and can set the stage for how one handles the future losses which life inevitably hands us all.

The Carters also encourage people "to take the issue of infertility off the back burner and deal with it again," stressing the idea that living without children is an option which should not be ignored until the end of the infertility journey. Rather, it is wise to include consideration of this possibility right from the start, along with all the other options being weighed, such as the medical, emotional and financial factors also involved. Therefore, if and when an infertile couple take the step not to have children, this is a judgment not by default but from a sense continued on page 8 V O I C E

CHILDFREE con't from pg 7... of active decision making in which "...loss (is) transformed into gain through the process of making a life decision." The very process of decision making helps to define and remove the obstacles which get in the way of moving on. It is important to remember that few lifetime decisions can ever be made with 100% certainty and that part of the process is to consider how much uncertainty (that is, regret or mixed feelings) you are willing—or able—to live with.

The decision for a childfree lifestyle may open options for including children in a manner other than child-rearing within a household. Nieces, nephews, children of friends, involvement with youth organizations—all

these children may benefit from the time and love that a childfree individual or couple has to offer.

There are also benefits conferred by the freedom that can accompany the decision to remain childfree. Freedom to travel, entertain, and spend time with one's significant other and with friends. These are some of the ways the authors have been able to "stop being infertile and start living again."

Kari Christianson and Amanda Sherman are DES daughters and Board members of DES Action. Both have faced the painful obstacles associated with the decision not to have children and both remain "childfree" today.

# We're now on the Net!

DES Action USA now has an email address. You can reach us by sending your e-mail to: desact@well.sf.ca.us

If you would like us to return your message via e-mail, be sure to add your net address to your message.

You can also always reach us by fax: (510) 465-4815

Our 800 Hotline number is: (800) DES-9288

Voice: (510) 465-4011

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