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Important Information About Mammograms

DES Daughters need annual mammograms but getting them is something of a mystery for most of us. Luckily, Jennifer Bailer is a DES Action member, a DES Daughter, and an RN working in breast cancer diagnostics. Bailer answered our questions during a recent discussion about mammograms on our DES Daughter On Line Support Group listserv. (See pg 2 for directions on joining because it is a benefit of DES Action membership for DES Daughters). We thank Bailer for her insights and received her permission to share with you the valuable information she gave our on line discussion group.

Q I have small breasts and mammograms are painful. When I am done, I literally see stars. I cannot walk straight and have to hold onto something. The last time I went to get a mammogram I asked the technician about extreme pain and why the compression was so great. She told me the state of New Jersey had raised the compression amount required on a mammogram.

A When having a mammogram, you have the absolute right to say, “That is enough. No more compression.” You can say please if you want to, but you have no obligation to do so. NO facility, NO state, and NO technologist have the right to put more compression on your breasts than you want — that would be assault and battery! That is against the law.

A patient has the right to refuse treatment and that includes refusing more compression than the tech says she needs, or the state requires.

Do NOT accept more than you can handle! Every woman perceives pain differently. You, and only you, can determine when enough is enough. YOU have the absolute right to say, “STOP”

What will happen if you say “Enough!”? The tech should stop. If the tech feels this is not enough compression, she will write “best films possible, patient refused further compression” in the notes section of the films being submitted for reading by the radiologist. The state cannot force women to have a certain amount of compression. States can say that a certain number makes for acceptable films, but they can’t tell you that you have to agree to a certain number.

Now, having said all that, you should also understand that adequate compression is essential for a good mammogram film. You will get a more accurate reading if you allow adequate compression. A cancer can hide in tissue that is not compressed well, and thus be missed. So DO allow as much compression as you can tolerate.

If the tech tells you there is not enough compression, and you think you can tolerate more, then go for it. The films will be better. If you can’t though, just say, “Stop.”

The respected medical facility, TRA Medical Imaging suggests the following to decrease pain and dis-

continued on page 3

Information Is Power — Tell Your Children About DES

By Fran Howell

You can’t change your genes, or the toxic exposures you or your parents faced, but knowing about them can spur you into taking the actions needed to protect your health. It may mean vigilance in having annual mammograms, or avoiding extra hormones, such as HRT. Knowing all the facts can lead to better health care decision-making.

In the case of DES exposure, our children depend on us to tell them what they should know. It is not an easy topic, but DES Mothers should inform their children and DES

Daughters and Sons should do the same for theirs.

If grandma had diabetes or dad has heart problems, it is common for the next generations to be made aware of it. The same should hold true for DES exposure, but in many families it does not.

Since we ran an article in the last VOICE (Fall 2008 Issue 118), we heard from several members about their experiences. This is from DES Daughter Elizabeth:

“I have two biological daughters, Lea, who is 23, and Rose, who is 18. Rose

continued on page 3



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Yes!—I want to join DES Action to stay informed and support a cause I believe in.

All members receive **The DES Action Voice** quarterly. Those at the **\$100 level and above receive an annual report on DES Action's work and progress.** All contributions are **tax deductible.**

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Please make checks payable to **DES Action.**

- I am a: DES Daughter DES Son Other DES Granddaughter or Grandson
 DES Mother of a: Daughter Son

NAME _____

ADDRESS _____

CITY | STATE | ZIP _____

PHONE _____

E-MAIL ADDRESS _____

Join OnLine Support Group for DES Daughters

Want to be in touch, via e-mail, with other DES Daughters? As a benefit of being a DES Action member you can join the DES Action Daughters On Line Support Group. That way you can ask questions and share experiences common only to those of us who are DES exposed.

To join the DES Action On Line Support Group simply send a blank e-mail to:
DESactionDaughters-subscribe@yahoogroups.com

You'll receive an e-mail back from Yahoo! Groups confirming your request to join. It offers two registration options and the easiest is Option 2. Click "Reply" so the note is sent back.

Once we've checked to be sure you are a current DES Action member, you'll receive a welcome to the group letter explaining how to send messages. Then you can participate in the e-mail conversations, or just quietly read and enjoy the learning experience.

MISSION STATEMENT

The mission of DES Action USA is to identify, educate, support and advocate for DES-exposed individuals as well as educate health care professionals.



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Mammograms from page 1

comfort: schedule your exam one week following the start of your menstrual cycle (or when your breasts are least tender), avoid caffeine for a week before your mammogram, consider taking Tylenol or Ibuprofen an hour before your mammogram, and consider taking Vitamin E to decrease tenderness (check with your doctor).

<http://tranow.com/faq/mammography.html#hurts>

You might ask if the facility offers something called a MammoPad. This is a foam type pad that sticks onto the mammogram machine before the breast is placed on it, something of a cushion. An added benefit is that it serves to cover up the freezing cold metal. Some women find it helps a great deal. Some think it doesn't make a bit of difference. The MammoPad usually costs \$5 and is not covered by insurance. www.hologic.com/wh/mammopad.htm

Q How do I know I am going to a good facility?

A As far as mammogram facility quality, the government has developed requirements. The Food and Drug Administration (FDA) sets and oversees the Mammography Quality Standards Act (MQSA). Every facility must adhere to these standards, and must be inspected yearly by the FDA and by the state. You can check this out at: <http://www.fda.gov/CDRH/MAMMOGRAPHY/>

Doctors who demonstrate a high level of knowledge can be certified by the American Board of Medical Specialties. You can check to see whether the radiologists at your facility are Board certified by looking them up at <http://www.abms.org/>

Q My mammogram clinic has digital mammography. Should I have that?

A You may wish to have a digital mammogram, especially if you have dense breasts, but film mammography is still considered the gold standard. However, a very large study showed that more cancers were found using digital mammograms, as compared with regular film, in the group of women who were pre-menopausal, under age 50 and with dense breasts.

You do NOT need a specific order for a digital mammogram. All you have to have from your doctor is an order for a mammogram. To make it digital just schedule the screening at a facility that has digital, and ask for it.

Some facilities have both digital and film mammography. Women who have no preference get whichever machine happens to be open when it is their turn. If you prefer digital, you should let the facility know when you schedule your appointment (and you may need to remind them when you get there, too). They should not mind accommodating your wishes.

DES VOICE

Tell Your Children from page 1

has cerebral palsy, developmental delays, a seizure disorder and vision impairment. Because of all we have been through with Rose, who was born prematurely as a result, I believe, of my DES exposure, Lea has always known about DES. Two years ago Lea was in extreme pain with what was probably a burst ovarian cyst. When I told the emergency room doctor about DES, I was glad it was not the first time Lea heard about it."

Mary, another DES Daughter, shared the reactions of her two 20-something children. She described how both her daughter and son wanted to ignore talk of DES.

"Justin did not like my mentioning to the doctor that I thought his testicular cancer might be a result of his grandmother being prescribed DES (and of course the doctor's reaction didn't help). Simone is good about getting yearly check-ups so that stuck, but she absolutely refuses to talk about DES, saying I am a "worrier." Despite her attitude, I will always share new research results she should know of, while hoping she

is right about my worrying needlessly."

DES Daughter Elane emailed her sons living across the country.

"I had actually never talked to them about DES at all before. Both responded with terse, but positive comments (as boys are likely to do when talking about rather personal information, such as doing self-examinations). It was not hard at all, and I was happy that I did it, and that they seemed to pay attention to what I said."

We have been asked whether it is prudent to tell DES Grandchildren about their family history of exposure when no specific health screenings have been identified for them. Of course, that could change, and unless they know about DES they won't be on alert for information they might need.

Currently, animal studies, which are good predictors of the human experience, tell us that we should watch for reproductive tract lesions in DES Grandsons, and DES Granddaughters may be at increased risk for tumors. The first study involving

humans shows DES Granddaughters taking longer to achieve regular menstrual periods than their unexposed counterparts.

We don't know, for example, what impact the hormones in birth control pills might have on DES Granddaughters. We hope for an answer in the near future, but science has yet to catch up with our concerns. That has been the situation all along with DES exposure. Similarly, doctors brush aside discussion of DES Grandchild issues. But to quote DES Action Co-founder Pat Cody, "that does not mean we need to be governed by their ignorance, arrogance and indifference." What we are going for is awareness. Perhaps long-time DES Action member Molly sums it up best:

"I have no children to tell. But I am deeply grateful to my mother for taking the issue seriously and telling us in no uncertain terms that DES was something we'd have to be conscious of our entire lives. I feel very lucky she told us, and I'm glad that she did."

DES VOICE

Don't Wait For Federal Regulators To Protect Us From A Chemical Similar To DES

By Fran Howell

The federal government can't decide whether a chemical used in many plastics and food containers is harmful, despite numerous studies showing that it is. Bisphenol A (BPA) is an estrogen-like chemical, much like DES, which is used in food packaging. The concern is that it can leach into food we eat and be absorbed by our bodies.

The litany of health problems linked to BPA sounds eerily similar to what we know about DES exposure. It is not surprising, given that BPA and DES are both synthetic estrogen-like compounds. Scientists, like Fred vom Saal at the University of Missouri, have found that BPA exposure can cause genetic abnormalities, along with an increased breast cancer risk. Published studies show that prenatal and perinatal exposures can cause a decreased sperm count and prostate cancer in mice, which are good predictors of the human experience. There is also evidence of chromosomal errors resulting in spontaneous miscarriages.

Last August the Food and Drug Administration ignored concerns about BPA and declared it safe, pleasing chemical companies that produce it. But their joy was short lived because just a few weeks later, an FDA subcommittee challenged the ruling. The new panel found that the FDA disregarded research showing BPA health risks when it went ahead and pronounced BPA safe.

In the face of this stinging rebuke of its ruling, the FDA has agreed to do another review of the safety of BPA.

How is it the agency came to conclude that BPA is safe in the first place? Critics maintain

that only studies funded by the chemical industry were considered, leaving out a multitude of independent research results saying otherwise.

Of highest concern is the growing understanding that BPA exposure in utero, and just after birth, can do the most damage. And where do we find BPA? It is frequently used in plastic baby bottles (!), along with plastic food containers and in the lining of metal cans.

Given what we know from our own experience with federal oversight of drugs and chemicals — or lack thereof — it seems obviously clear that our best course of action is to employ the precautionary principle with BPA. In a nutshell, it tells us to act in protecting our health when there is credible evidence of harm, rather than wait for absolute proof.

Specifically, pregnant woman should avoid canned goods where BPA leaches into food from metal linings, and after their babies are born, they should avoid polycarbonate plastic baby bottles and sippy cups because they are made with BPA. This is incredibly important, as BPA studies show it is a health hazard to developing bodies in phenomenally small amounts.

There are alternatives. Glass baby bottles are an option, as are those made of pliable, milky-colored plastic because they don't contain polycarbonates. Some manufacturers are coming out with BPA-free baby products, but you will have to look for them.

While the immediate concern is for infants, there is BPA in plastics all around us. Reusable water bottles are a good example. The Centers for Disease Control and Prevention estimates about 93 percent of Americans have traces of

BPA in their bodies because BPA is pervasive in the plastics we come in contact with every day.

As individuals affected by the similar estrogen-like compound, DES, we can act to protect our health by avoiding BPA when possible, and by warning family and friends about the danger. Go on line and learn what you can (e.g., download "Shaping Our Legacy," see page 6 of this issue). Don't wait for government regulators to restrict the chemical in food packaging. They may never do it. Remember, they still have not banned DES for human use.

Free Teleconference Series for Cancer Survivors

While not specific to DES-exposed individuals, many of us deal with cancers, so we thought you should know that registration is underway for the Seventh Annual Cancer Survivorship Series: Living With, Through and Beyond Cancer. The teleconference sessions are sponsored by CancerCare and the National Cancer Institute.

This three part series offers cancer survivors, and their families and friends, practical information for coping with concerns and issues that arise when treatment ends.

The teleconference calls will be held on April 14, May 19 and June 23 from 1:30 to 2:30pm eastern time. Discussion topics include Managing the Stress of Survivorship, Nutrition and Physical Activity, and Managing the Fatigue of Care Giving. Experts in these fields will lead the discussions.

The teleconferences are free, and no phone charges apply. However, pre-registration is required. To do so go to the CancerCare website, www.cancercare.org/TEW.

DES VOICE



Drug Firms Limit Small Gifts to Doctors—But Not Big Ones

By Fran Howell

While in my doctor's waiting room a few days into the New Year, I was surprised to see a drug company representative stride up to the receptionist and discuss a drug he was promoting, while subtly mentioning the lunch he was providing for staff later that day. I didn't think they were allowed to do that anymore.

But voluntary drug marketing guidelines established by the pharmaceutical industry itself apply only to a ban on trinkets, such as drug-name branded pens, coffee cups and notepads given in the hopes of influencing the prescribing habits of doctors.


So those small drug company gimmicks should be gone from doctors' offices when they are used up. Doctors will now be buying their own soap dispensers, paper clip holders and tongue depressors without drug names emblazoned on them.

Proponents view this as a welcome first step in limiting drug maker influence on the prescriptions doctors write. As a DES Daughter, I'm especially sensitive to this, knowing how hard pharmaceutical companies promoted DES to doctors even after studies showed it didn't work.

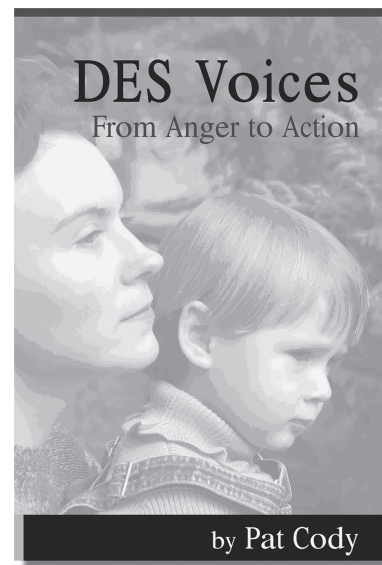
Those disappearing trinkets are merely the tip of the iceberg in a sea of pharmaceutical spending on doctors estimated in the billions. You can see why critics, like DES Action, are skeptical. The new voluntary code of conduct does not address really big money doctors get from drug companies in the guise of consulting fees, speeches, and trips to sunny climes that will continue behind the scenes.

To address this pharmaceutical influence, DES Action is a member of the Prescription Project, which is

working for Congressional passage of the Physician Payments Sunshine Act. It would establish uniform maximum amounts for meals, gifts, honorariums and other payments, to be applied nationally. At this time each state must pass its own rules regarding amounts that drug companies can give to a doctor. Some already have passed legislation regulating gifts to physicians, but most have not. As part of the proposed law, drug companies would be required to disclose gifts and payments that add up to more than \$100. The amounts of these payments and gifts would be listed online in an accessible database. Then we'd know the true scope of pharmaceutical marketing efforts that influence which drugs doctors prescribe to us.

While the drug representative visiting my doctor was carrying a smaller bag, sans little freebies, he was still buying lunch for the office to promote his product. I don't know, but I assume the doctor ate better than I did that day. 

Read Our DES Story



To order a copy of *DES Voices: From Anger to Action* send \$12.95 for each book (which includes shipping) to:

DES Action
187 Via Catalunha
Jupiter, FL 33458

Don't forget your name, mailing address and contact information in case we have a question about your order.


At Last—A Real Watchdog at the FDA

By Pat Cody

Dr. Sidney Wolfe, director of the Public Citizen Health Research Group and one of DES Action's heroes honored last year, has been appointed to a four-year term on the Drug Safety and Risk Management Advisory Committee of the Food and Drug Administration (FDA). Never was an honest voice for consumers more sorely needed.

We regard as a compliment the way the Wall Street Journal reported on the Wolfe appointment. "The pharmaceutical industry has

a recurring nightmare: drug safety crusader Sidney Wolfe becomes a player at the Food and Drug Administration." Nightmares for them are dreams come true for us.

Dr. Wolfe was the earliest whistle-blower on DES in 1975, and has been a stalwart supporter in our efforts for more research and for accountability by drug companies. His work led to the withdrawal of 16 dangerous drugs from the market, and requirements for warnings on many products that bring billions of dollars to the drug industry. 

Shaping Our Legacy: Reproductive Health and the Environment

Reviewed by Kari Christianson

In January, 2007, the University of California San Francisco (UCSF) and the Collaborative on Health and the Environment (CHE) brought together over 400 research professionals and health advocates with two goals:

1. to review current scientific understanding linking chemicals with impaired fertility and reproductive health;
2. to discuss new research directions, clinical care approaches, educational tools and policy initiatives to improve fertility, pregnancy outcomes, development and reproductive health.

While it took almost two years for this complete report of the proceedings to be published, it's a blueprint for understanding the known and suspected ill effects of chemicals on

reproductive health and fertility. Exposure to endocrine disrupting chemicals occurs both environmentally and pharmaceutically.

The harmful effects of DES exposure provided the first reason for studying impaired reproductive health. A chapter title in this booklet says it all — “DES: Harming multiple generations in multiple ways.”

While the understanding that chemicals and other hormonally active substances can and do have far-reaching effects on human health, fertility and reproduction started with DES exposure, generations of DES-exposed continue to be a vital part of research opportunities.

The on-going study of generations of DES-exposed humans informs all endocrine disruption research. But much more research and government action is needed to understand the

multiple exposures to many different hormonally active substances that are affecting current and future generations.

The chart on the next page (created by Lauren Wohl Design for the Shaping Our Legacy report) lists areas of known DES effects in humans and suspected effects based on animal studies.

Currently, this report is being used by those who attended the summit and new CHE partners to assess what has been accomplished in the past two years and what goals remain to be met.

The report is available for download free of charge at www.prhe.ucsf.edu/pubs/shapingourlegacy.html or a printed copy may be ordered for \$5 (for the U.S. and Canada) or \$10 (for all other countries) from:

UCSF-PRHE
1330 Broadway St., #1100
Oakland, CA 94612



Stopping Hormone Use Reduces Breast Cancer Risk

By Pat Cody

A new study on hormone use and breast cancer, reported in December, shows that when post menopausal women quit hormone treatment after short-term use, their breast cancer risks returned to normal levels within two years. This research, reported at the San Antonio Breast Cancer Symposium, looked at records from the Women's Health Initiative.

However, breast cancer for over 16,000 women who had already been on hormones for an average of seven years was double the risk for the control group of women who had never used HRT.

Specialist Claudine Isaacs, M.D., from the Lombardi Comprehensive Cancer Center at Georgetown University told a reporter, “It's an excellent message for women. You can still diminish risk (by quitting) even if you've been on hormones for a long time.”

The lead author, Rowan Chlebowski, M.D., from Los Angeles, advises women to use hormones only if menopausal symptoms are severe, and then for the shortest time and lowest dose. She points out that most women will not develop breast cancer after short-term use, since the risk accumulates with each year of use.



What We Can Learn From Starlings



By Pat Cody

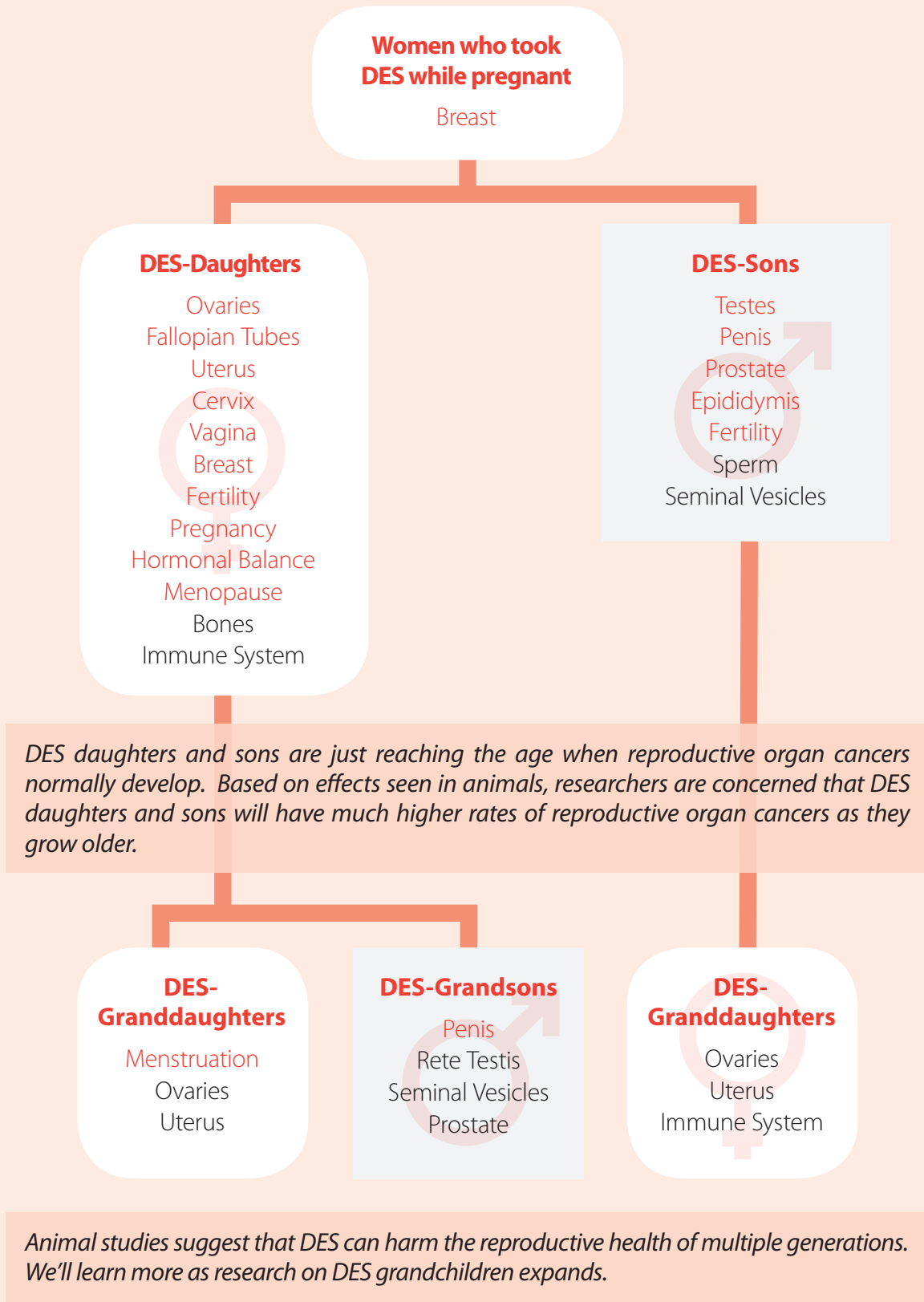
“Pollutants Increase Song Complexity and the Volume of the Brain Area HVC in a Songbird,” S. Markman et al, *Public Library of Science (PLoS-One)*, Feb. 27, 2008.

Early research on DES began a new field of inquiry now termed endocrine disruption. Many stories tell of deformities in birds and fish living near polluted rivers and lakes. This study demonstrates effects on neural development in male starlings that were given estrogenic chemicals like those found in worms from sewage plants where wild starlings forage.

The scientists report the brain area where song complexity is created became over-developed, so the songs were more complex. These starlings also showed a weakened immune system. Female starlings chose these less fit mates over more robust males whose songs were inferior. This has potential effects on their offspring, a warning lesson on the future of the starling population, and something to think about when considering the number of estrogenic chemicals we are all exposed to on a daily basis.



Reproductive Organs and Functions Harmed by Taking DES During Pregnancy



Red = effects seen in humans.

Black = effects seen in animals and therefore possible in humans.

From *Shaping Our Legacy*, a publication of the UCSF Program On Reproductive Health and the Environment



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Moving? Please let us know...

This poem first appeared in the VOICE in 1989. DES Mother Fay Cohen dedicated it to all the special DES Mothers she had spoken with over the years. Her poetic message also brings to mind the importance of “Telling Your Children,” which needs to part of your — and their — DES experience through the generations.

My Wonderful Transition: From DES Mom to DES Grandma

By Fay Cohen

*I've lived through days and nights of fear,
The unknown risks for one so dear.
I watched her grow from tot to teen,
and wondered how I'd find the means
to help her through her toughest days.
Somehow, I managed to find my ways.

The years passed by — she met her mate;
The joy and excitement of the wedding date —
Before you know it, she's leaving town;
It's time for her to settle down.*

*Now I wait and wonder and pray
Will she have children of her own one day?
Time passes on, and praise the Lord
She's pregnant, on bed rest and very bored.
The high-risk scene we must sweat out
But finally, no room for doubt —
She reaches term: her baby's here.
Have you ever seen anything quite so dear?

Oh yes, I've lived with times of fear —
But thankfully, I am still here.*

DES VOICE