

Medical Reports

Heart Disease, HRT, and Vitamins

by Pat Cody

POST-MENOPAUSAL women with heart disease can be harmed by either Hormone Replacement Treatment (HRT) or the antioxidants vitamins C and E. Most DES mothers are post-menopausal, so, while this study did not screen for DES exposure, we need to pay attention.

The *Journal of the American Medical Association (JAMA)* carried a report in its November 20, 2002 issue by David D. Waters MD and 15 co-authors. They described the Women's Angiographic Vitamin and

"There are lots of things that work well – diet and exercise, lowering cholesterol, controlling blood pressure. We should be focusing on things that work."

Estrogen (WAVE) trial of 423 post-menopausal heart patients over 65. The researchers found that those who were treated with either/and HRT and Vitamins C and E had greater rates of death, heart attacks and strokes. Their

conclusion:

"In postmenopausal women with coronary disease, neither HRT nor antioxidant vitamin supplements provide cardiovascular benefit. Instead, a potential for harm was suggested with each treatment."

Dr. Waters told the *San Francisco Chronicle* that for such women, "there are lots of things that work well – diet and exercise, lowering cholesterol, controlling blood pressure. We should be focusing on things that work."

Yearly Tests Needed

IN our Fall 2002 issue we printed a statement from Arthur Herbst M.D., leading expert on clear-cell cancer (CCA). He emphasizes that

"The DES exposed without

CCA at a minimum need an annual pelvic examination." We bring this up because in December the American Cancer Society issued new guidelines for cervical cancer screening. According to the *New York Times* report:

"At or after age 30, women who have had three normal tests in a row no longer have to be tested every year. They can be screened every two or three years, though more frequent tests may be recommended for women with H.I.V. infection or certain other health problems."

While DES daughters fit the category of "certain other health

"The DES exposed without CCA at a minimum need an annual pelvic examination."

—Arthur Herbst M.D.

problems" we have a concern that HMOs in particular will have a general policy that can make it difficult for DES daughters to get the care they need. We think that daughters should keep Dr. Herbst's statement in their health files to use if necessary.

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How to Join the DES Daughters Listserv

DES Daughters should check out DES-L, the DES daughters listserv and online support forum at http://www.surrogacy.com/online_support/des/. To join the listserv, complete the online application and get ready to share support and information with 1,000 other DES daughters! Note: this list is operated independently from DES Action.



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

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 Mother of a: ☐ Daughter ☐ Son

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DES Action Affiliates

Each affiliate was created and nurtured by volunteers. Write to them if you want information or would like to volunteer.

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New Jersey
New Mexico
Ohio
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Texas

DES Action International

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DES Action Survey

DES Action is proud to have reached its 25th year milestone. With the CDC DES Education update beginning this month, we have so much to be proud of. A great many individuals have contributed to our successes - most importantly - those of you in our membership. Some of you have been with us the entire 25 years, while others have become acquaintances only recently. We are grateful for your involvement and support now and throughout the years.

As part of a continuing effort to evaluate our overall effectiveness as an organization, and to help direct our efforts and activities into the future, we want to hear from you! We ask that you take a few moments to answer the questions in this short survey:

Please note - all identifying information will be held strictly confidential unless otherwise indicated by you.

Name (optional)

City/State

Age

I am a DES:

- ☐ Mother (first generation)
☐ Daughter (second generation)
☐ Son (second generation)
☐ Granddaughter (third generation)
☐ Grandson (third generation)
☐ Other _____

3) What issue(s) most concerns you today?

4) How long have you been a member?

_____ years _____ months

5) Here are a list of our services:

- Quarterly Voice Newsletter
- Physician Referral
- Attorney Referral
- Advocacy for Research
- Legislative Updates
- Conferences
- DES Sons Network
- DES Third Generation Network
- Website
- Toll-free hotline
- Publications

a. What services do you benefit from most and why?

1) How did you hear about DES Action?

2) What issue(s) motivated you to join DES Action?

b. What services can we improve upon, and how?

c. Are there services we do not currently provide that you would like to see initiated? If so, please list them here.

6) Do you know of any DES-exposed individuals within your own community/state?

☐ Yes ☐ No

7) Would you be interested in initiating a state/community affiliate group?

☐ Yes ☐ No

8) If a DES Action group existed in your area, would you be interested in joining it?

☐ Yes ☐ No

9) Would you attend a national conference (at your own expense) if it were held to bring affiliate groups together and network?

☐ Yes ☐ No

Comments:

If you answered 'NO' to question 9, please skip 9a and 9b and move to question 10.

a. What specific issue would you like discussed in a national conference/forum?

b. Who should speak at this conference? Who would you like to question or hear speak?

10) We are proud of the fact that we do not take money from pharmaceutical companies to fund our operations. Yet we are continually concerned and challenged – especially in this downturn economy – on how to raise funds to keep our operations going. If you have innovative ideas on how to raise funds, please share them with us:

11) What areas of research do you feel we should promote?

☐ DES Sons

Specific issues? _____

☐ DES Daughters

Specific issues? _____

☐ DES Third Generation Effects

☐ Menopause and Aging

☐ Autoimmune Issues

☐ Other

The CDC's DES Update has begun, and we are looking for your input and for members who are interested in helping disseminate information. The following questions focus on the CDC's DES Update.

12) What kinds of activities would you like to see happen nationally and/or locally during or beyond the CDC's DES Update?

13) Are there any activities within your community (health fairs, conferences, etc.) where information on the CDC's DES Update can be distributed? If yes, please indicate:

14) Would you be willing to help disseminate information about the CDC's DES Update at any of these activities?

☐ Yes ☐ No

15) If you are willing to be interviewed about your DES story for your local newspaper or news media outlet, please briefly describe your story and leave your name, email address, and telephone number here:

16) Additional Comments:

We thank you for your participation in this survey. Please feel free to contact DES Action at any time with your comments, questions, or concerns.

The results of this survey will be published in summary form in a future issue of the DES Action Voice, and will be used to help DES Action improve our services to our members.

Please return the survey by March 15, 2003 to:

DES Action USA, 610 16th Street, Suite 301, Oakland, CA 94612

If you do not wish to tear out the survey and mail it to us, please copy the survey with your answers and send it to us. Feel free to add extra paper if you need more room.

You may also fax the survey to our office at 510-465-4815.

On The Cutting Edge:

An Interview with Davis Baltz

by Nora Cody

WITH this issue, we kick off "On the Cutting Edge," a Special Series of Interviews with individuals who we believe are working on the cutting edge of public health advocacy, scientific research, environmental activism, and community empowerment.

Our first, two-part interview took place in January and features a conversation with environmental and health activist Davis Baltz. Davis works in Oakland, California for the nonprofit organization Commonweal. DES Action and Commonweal work together in the Collaborative on Health and the Environment, a new coalition.

Because the interview was too long for this issue, we have split it into two parts, with the next installment slated for our Spring, 2003 issue.

I know that you work for Commonweal. For our readers who may not be familiar with Commonweal, can you tell us about your organization?

Commonweal, founded in 1976, is a non-profit health and environmental research and service institute in Bolinas, California. The principal areas of work are with

(1) people with cancer and health professionals who work with people with life-threatening illnesses;

(2) children and young adults with learning and social diffi-

culties, and the childcare professionals who work with them; and

(3) the global search for a healthy and sustainable future.

More information on all of the activities, as well as a list of our publications and tapes, can be found at our website: www.commonweal.org

What is your background and how did you get involved in this work?

I started working at Commonweal in 1995 after several years of working on environmental education & training and human rights programs in different Asian countries. For example, I evaluated farmer training programs to reduce pesticide use in Indonesia, supervised refugee resettlement in Thai refugee camps, observed elections in Sri Lanka, and assisted community organizing efforts with farmer groups in the Philippines. I have a Masters degree in International Community Economic Development.

You are currently working primarily on two projects, biomonitoring in California and you are the California Coordinator of Health Care Without Harm. Let's start with biomonitoring. I know that the CDC is set to release an important report at the end of January that will give us new

information about levels of toxins in the American population. Can you explain what biomonitoring is, its purpose, and what you hope to accomplish in your work?

"Biomonitoring" is the direct measurement of chemical levels in blood or urine. The resulting data of what a person actually carries inside is called "body burden."

There are two reasons why biomonitoring is important. First, it allows trends to be studied by establishing baseline data. Later measurements can be compared to earlier ones to determine if more or less chemical exposure is occurring.

Second, when an individual or community has actual numbers that correspond to chemical exposure, it opens great possibilities for organizing to eliminate the chemical trespass that has taken place without our consent.

I know that you had your own blood and urine tested, along with other staff at Commonweal, to measure the levels of various toxic substances in your body. Can you talk about what you learned, how you felt about it, and how you think this kind of individual knowledge relates to the work you're doing?

As a DES son who works as an environmental advocate, I

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had a pretty good idea of what my own body burden would be before I was tested. But I was still shocked when I saw the numbers. There were a total of 106 compounds found in my blood and urine, including dioxins, furans, PCBs, pesticides (both organophosphate and organochlorine), metals, phthalates, and semi-volatile organic compounds. Some of the levels were higher than is considered "safe" by government regulators.

For me, after the shock came anger. I did not give permission for my body to be the dumping ground for the toxic products of petrochemical companies. There was also the realization that widespread chemical exposure is not unique to me – everyone in our cohort had similar (but not identical) numbers. The sad fact is that everyone in the United States, and indeed the world, now carries a chemical body burden. Virtually none of these chemicals had been synthesized at the time my parents were born in the 1920s.

As an adult, some of my chemical exposures will probably not be a problem for my own health. This is because many of the adverse effects are developmental in nature, meaning that children are the ones most at risk. Their organ systems are still developing and extremely sensitive to chemical insult. This is a concept that is tragically familiar to the DES Action community.

There is no escaping the terrifying reality that we are conducting an uncontrolled chemistry experiment with our children as the subjects. And

furthermore, at this time there is no accountability for the producers of these toxicants. We have allowed a regulatory system to take root that assumes chemicals are innocent until proven guilty until there is a "body count."

We are hopeful that biomonitoring will advance our policy work focused on the "Precautionary Principle," which is a tool to make better environmental decisions. It says that when there is evidence of harm, there is an obligation to take precautionary measures even if some cause and effect relationships are not fully established scientifically. In plain English, the Precautionary Principle means "better safe than sorry."

In the case of toxic chemicals, we make the argument that the actual numbers from our own body burden indicate there is evidence of harm. In my own case, for example, among the 106 chemicals in my body, 62 are carcinogenic. This fact should compel us to adopt policies that are more precautionary, resulting in reduced exposure to potentially harmful substances. The Precautionary Principle aims to shift the burden of proof onto producers of chemicals, rather than the public, so we can have reasonable scientific certainty that a chemical is safe before releasing it into the marketplace and the environment.

What can people do to help support your efforts to further biomonitoring?

Ideally, more participants in biomonitoring studies could be

tested. This would yield useful data, and also hopefully catalyze new organizing. Unfortunately, the cost of producing an extensive body burden profile remains prohibitively expensive.

As you noted, on January 31, 2003, the federal Centers for Disease Control and Prevention (CDC) issued its Second National Report on Human Exposure to Environmental Chemicals. The first report, in March 2001, measured 27 chemicals in a broad cross-section of the American people. The new report examines the body burden of 116 chemicals in Americans. It is critical that the CDC continues to issue these reports on a regular basis so that the public can see the direction of emerging trends.

Ed. Note: to see this report in its entirety, go to <http://www.cdc.gov/exposurereport/>

Immediately prior to the release of the CDC report, the study of body burdens for people at Commonweal was publicly released in collaboration with the Mt. Sinai School of Medicine and the Environmental Working Group. The results of this study are online at: <http://www.ewg.org/reports/bodyburden/>

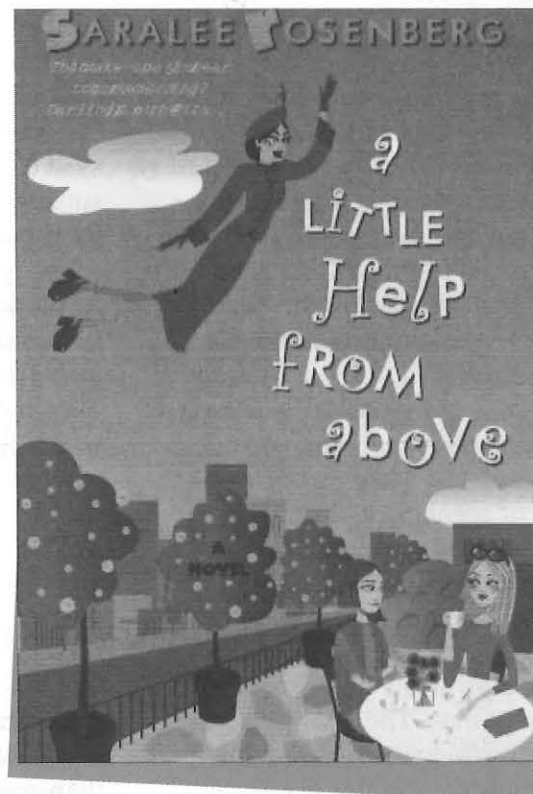
Meanwhile, in a separate track, the State of California is preparing a proposal to the CDC whose goal is to increase the biomonitoring capacity within the state. The proposal, due in June 2003, could be worth several million dollars over several years, and would allow California to develop biomonitoring projects and strategies that will tell us much more detail about our chemical body burdens and their sources. ■

BOOK NOTES

A Little Help from Above, by Saralee Rosenberg, 2003. \$13.95. Avon Books.

MS Rosenberg's novel deals with two sisters, one of whom is a DES daughter with infertility problems. There's a fantasy element of their mother in heaven intervening now and then to smooth the path of fractious relations between the sisters, but most of the story is rooted in real life challenges. Shelby is a single career woman of 38 and when she goes back to their family home on Long Island, she learns about her younger sister Lauren. Because they have not been close in

years, Shelby did not know that Lauren, a DES daughter, needs a surrogate if she is to be a parent. Shelby has another concern – her long-lost love from her childhood. But the main story is about DES. The more Shelby understands, the harder it is for her to let her sister face her troubles alone. It's a rocky path with twists and turns before a resolution is reached for both of them – and for Shelby's future. ■



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