DES Action VOICE

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A FOCUS ON DIETHYLSTILBESTROL

SUMMER 2006 #109

Successful Lawsuits for Premature DES Grandchildren

By Fran Howell

Since 2004, seven DES premature birth cases were filed by Aaron Levine and Associates (www.aaronlevinelaw.com) in U.S. District Courts for Boston and California. These cases were resolved in favor of the DES preterm injured children. Through the use of structured settlements, they obtained a total of more than $20 million dollars, to be paid throughout their lives for therapy, special education and loss of earnings. There are also opinions in Maryland and Philadelphia upholding the rights of DES preterm injured children to proceed to a jury trial, and the cases were all resolved favorably for the infants.

These cases concentrate on DES premature grandchildren who live normal life expectancies but suffer a range of impairments from moderate learning disabilities to devastating handicaps and who, "but for" their mother's *in utero* DES exposure, would have gone to term and lived normal, healthy lives. The cases described here do not cover a range of DES injuries, including miscarriages, stillbirth, or the death of preterm children that DES Daughters suffer.

As part of his argument before the California court, Levine compared a DES uterus to a hypothetical badly built balcony that fell and injured children six years after construction. He explained that the defendant (drug maker), "by its failure to test and failure to warn of known risks, built a defective uterus (in a DES Daughter) just as a builder might build a defective balcony. The delay in the resultant injury is inherent in the nature of the uterine structure in that it had a 30-year wait to be called upon." In this case, Levine says the children were seriously disabled "because they fell 16-weeks early from their mother's Dienestrol-caused stunted uterine structure."

While preparing the cases, Levine and his staff uncovered studies going back to the 1930's which describe malformations of the uterus and cervix in animals from *in utero* exposure to DES and estrogen. He found that many tissue abnormalities in exposed offspring were reported in France and England as well as America and were never followed up by the manufacturers before or during their promotion of DES. Tissues of the female reproductive tract have always been known to be estrogen sensitive. Levine says, "reports go back over a hundred years of stunted uteri in animals from excess estrogen exposure (whether synthetic or natural). In the 1950s many drug companies were doing generational studies on the effects of their drugs on the children of pregnant mothers, but not the DES manufacturers. The DES companies did not do any testing, nor did they do any controlled studies on efficacy."

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Potential Health Risks for DES Grandchildren Shown In Studies — Researchers Want To Know Why

"Adverse Effects of the Model Environmental Estrogen Diethylstilbestrol Are Transmitted to Subsequent Generations," by Retha R. Newbold, Elizabeth Padilla-Banks, and Wendy N. Jefferson, Endocrinology, June 2006.

Reviewed by Fran Howell

If you give a female mouse DES during the time of development, results are the same as found in human DES Daughters — cancers, infertility, reproductive tract abnormalities, etc. So what happens to the children of these mice?

At her lab at the National Institute of Environmental Health Sciences (NIEHS), researcher Retha Newbold bred DES Daughter mice with untreated males, making the offspring DES Grandchildren mice.

The male offspring of DES Daughter mice showed an increased incidence of proliferative lesions of the rete testis (tiny ducts connecting testicular tubules with the epididymis, which is an estrogen target tissue in the male). The rate of lesions ranged from eight to 35% in the DES Grandson mice, based on the dose and timing of exposure for the grandmother mice.

Newbold also found other reproductive tumors in DES Grandson

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To join the DES Action Sons On Line Support Group simply send a blank e-mail to:
DESactionSons-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.

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Successful Lawsuits *from page 1*

According to Levine, successful DES Grandchild cases were made difficult to file because of two old and restrictive appellate decisions from New York and Ohio. The courts denied compensation for preterm injuries because they were too remote from the ingestion of the drug. The judges ruled in those cases that a drug manufacturer in the 1950s could not be expected to anticipate a grandchild injury.

Levine's office made these successful arguments to the court in this year's litigation:

1. Those cases (from NY and OH) are old and no longer reflect current legal thinking;
2. DES was a target drug aimed at the female reproductive tract and it doesn't take a rocket scientist to realize that if you meddle with the reproductive tract of the mother you risk deforming the reproductive tract of the daughter – DES was given to two individuals;
3. the DES preterm grandchild's birth uterus was impacted by DES because the actual drug came into contact with the actual birth uterus and therefore the injury is not remote;
4. it would be unfair to deny these children compensation for an injury when other preconception torts are compensated (for example, failed tubal ligation and wrongful birth cases);
5. the fact these injuries manifest themselves 30 to 40 years after the prescription should not benefit the drug companies since it was their fault — they built the time bomb with a 30-year fuse.

With current rulings now turning in favor of compensation for DES Grandchildren, Levine is confident that courts will look more favorably upon future cases. He believes the climate for such lawsuits has been significantly improved. "While infertility, miscarriage, and ectopic pregnancy continue to haunt DES Daughters, their preterm children are a major part of our current efforts," he says. DES VOICE

Risks for DES Grandchildren *from page 1*

mice, but to a lesser extent. They ranged from one to three percent so the incidence of actual tumors in these mice is low.

DES Granddaughter mice were also susceptible to tumors, with 11% developing the growths. Their mothers (DES Daughter mice), showed a tumor rate of 31%. Clearly, tumor rates decreased into a subsequent generation but are still significant.

Researchers now want to know why DES Grandchildren mice are at higher tumor risk than unexposed mice. According to Newbold, "These data suggest that alterations occurred in germ cells and were passed to subsequent generations."

What causes health problems for DES Grandchild mice is still a mystery, but scientists are moving closer to an understanding. Newbold says one possibility is that prenatal DES exposure alters the process called methylation, which is how a gene is switched on at a certain time to do what it is programmed to do.

She continues, "we have shown altered methylation patterns in several uterine genes that are permanently dysregulated after developmental DES treatment." Newbold concludes that, "because the response of *estrogen-regulated genes* is set during development, altered hormone response may be transmitted to subsequent generations."

Another avenue of study looks at transgenerational DES effects associated with changes in specific *estrogen-responsive* genes. Researchers have shown that prenatally exposed DES mice can have an overexpressing estrogen-responsive gene (uterine lactoferrin), meaning it gives off more signals than normal. Importantly, Newbold says researchers found the same gene overexpresses in uterine tissues of DES Granddaughter mice, even though these mice were not directly given DES.

DES Granddaughter mice were also susceptible to tumors, with 11% developing the growths. Their mothers (DES Daughter mice), showed a tumor rate of 31%.

Newbold cautions that more studies are needed to conclusively prove that what happens to DES-exposed mice also occurs in humans. She urges researchers to pay attention to the DES community, and especially the grandchildren of DES-exposed women, because "evidence with experimental animals suggests that adverse effects may be transmitted to subsequent generations," as happens in the mouse population. DES VOICE

Well-deserved Recognition for a DES Plaintiff Attorney

By Pat Cody

Nancy Hersh of San Francisco is a pioneer in DES work, going back to the late 70's. She created a "Manual for Lawyers," for those interested in taking DES cases, and DES Action sold those manuals as an important fund-raiser in the early 80's.

Now, many product liability cases later, Nancy has been singled out by *California Lawyer* magazine as one of 47 attorneys in the state "whose work has had a significant impact in 2005."

The citation for Nancy is in the Personal Injury category. She was the first to file a Zypresa-related suit against Eli Lilly (!) and represented 430 individual cases in the coordinated litigation. Eli Lilly agreed to pay $690 million to settle claims from over 8,000 patients who had side effects, such as early onset diabetes, from this anti-psychotic medication.

One of her co-counsels in the multidistrict litigation, Jerrold S. Parker, told the magazine, "Hersh is one of the rare ones. She was extremely instrumental in making the settlement happen as quickly as it did." DES VOICE

YOUR VOICE

The following article, by DES Action member Elizabeth Kate, is another in a recurring series of personal stories to be published in the VOICE. We hope you will enjoy reading about the spirit of our members who are living good lives in spite of, and with, DES exposure. Do you have a DES story that communicates hope? Please e-mail Board Member Ann Giblin, Ann@WinterlakeAssoc.com, for more information.

By Elizabeth Kate

My mother told me I was a DES daughter when I was 15. The news was a lot for my adolescent self to grasp. My first thought—how very unfair that I had to deal with DES while both of my sisters got off scot-free. My second thought— the horror of the possibility of having cancer of the VAGINA. The sheer embarrassment would take me out long before the cancer ever would.

It didn't faze me that there was a possibility that I might have difficulties getting pregnant. My babysitting experiences had convinced me I didn't like kids all that much. My mom's gynecologist suggested I might feel differently when I grew up. She reassured my mother and me that I didn't have cancer, but that I did have the cervical adenosis commonly seen in DES daughters. She said the future would tell about problems with getting pregnant or carrying a pregnancy. I was relieved that this DES was not going to demand my attention for some years to come.

I was 29 and about to get married when, having changed my opinion of children, DES again became a topic of discussion, this time between me and my fiancé, Peter. The dear man told me that he was happy to adopt if we weren't able to have biological children. I liked the idea of adoption, so this sounded like a fine plan to me. We decided to try for a baby immediately.

After two years as blissful newlyweds sans birth control, it became apparent we were no closer to being a family. We decided to consult a doctor. Consulting a fertility doctor was unnerving as it made the problem real, yet it did hold the promise of a solution. After following this doctor's advice, Peter and I would enthusiastically fantasize about what surely was our rapidly approaching parenthood. Six months later, the sheen had worn a bit thin.

The doctor recommended I get a hysterosalpingogram. He said a side benefit of this procedure could be to "clear out the cobwebs" in my fallopian tubes – that many of his patients got pregnant soon after they had this procedure done. The result was he had a clear picture of my "classic DES T-shaped uterus" and I did not get pregnant. He recommended another procedure, a laparoscopy/hysteroscopy.

It was at about this time that my husband accepted a new job in South Africa. We decided I would have the laparoscopy/hysteroscopy done there. I actually looked forward to the surgery – it held the promise of having answers as to why nothing was happening. I had the surgery. Once again our hopes rose.

Four months after the surgery and we were back in the doctor's office. Thus began our journey down the long and twisted road of fertility treatment. We slogged through seemingly endless IUIs and IVFs, ever-hopeful, yet ever-crushed when yet another month passed without success.

The fertility treatments became much like a drug addiction — we couldn't stop. Each month ended in tears and disbelief, and just enough hope to try again. Just one more time. Next time will be different. Next time I'll be better. Next time we'll try this. Or that. Next time. Next time. The doctors won't tell you to stop, because fertility is their business and as far as they're concerned there's always one more treatment on the horizon.

After two years of this heartbreak, I put on the brakes. In spite of all our best efforts, hopes, dreams and of course many, many dollars, we were still childless and I was somehow lonelier than I ever felt possible. I couldn't do it anymore. We decided to stop treatment and take a breather.

I took a lot of long walks and searched my soul, seeking to sort through my crumbled emotions. After a few months it was clear: I wanted to be a mom and I wanted to love a child. I didn't care where that child came from but wanted to find that little spirit who danced through my dreams. I was certain the right child would come to us. Peter agreed – we were finished with fertility treatment forever. We registered to adopt in South Africa, enthusiastic and positive once more.

A year later, we returned to the USA. Four years later — four years of pendulum swings of holding onto and then losing hope, four years of my trying to get back to my old life before the baby craziness began, we got the

call — a birth mother had chosen us.

Thrilled, eight years after trying to start our family, we flew to South Africa to meet "Susan" who was five months pregnant with our baby girl. At last — our angel had arrived. We would be back in four months to bring our little girl home with us. And then, three weeks before our departure overseas, I got sick.

I had been constantly worried — so much had gone right, but so much could still go wrong. I knew beyond a doubt that this little baby girl was meant to be ours, but it did not alleviate my nervous stomach. A few days later I realized the stress — or was it early menopause? — was also causing my period to be late. I made an appointment with my gynecologist.

Later that day, in the grocery store I found myself staring at pregnancy test kits, silently arguing with myself. Should I be an absolute idiot and plunk down twenty bucks for a test when I knew very well there was no way in the world I was possibly pregnant? I had embraced adoption and honestly didn't want to get pregnant anymore. I was going to be the mother of a beautiful child without ever having to deal with morning sickness or the throes of childbirth. How could that be more perfect? I tossed two tests in my cart.

The next morning, racing to get dressed to meet a friend, I remembered the pregnancy tests and decided to give one a try before I left. At least I could put my mind to rest and stop entertaining ridiculous notions of pregnancy. A single butterfly fluttered through my stomach as I pulled out the stick. Two dark blue lines crisscrossed the stick. Two? I grabbed the box out of the trash and re-read the instructions. Two stripes: Positive. I took a deep breath. Pregnant. How was this possible? It wasn't possible. It was a miracle. Or a horrible mistake. I took the second test. Pregnant.

That night, Peter stared blankly at the test stick in the jewel box I had handed him, and then back to me. "I'm pregnant!" I whispered. "At least, that's what this test says." In spite of my doubts, together we shared our surprise, joy, and apprehension.

Waiting in my gynecologist's office a few days later, nothing seemed real. I wondered if a huge joke was being played on me. I fidgeted, as a pregnant woman sitting across from me flipped through a "Your Pregnancy" magazine. Where was that doctor? I hated being around pregnant women— look at her, all smug in her bountiful fertility. Damn. Where was that doctor?

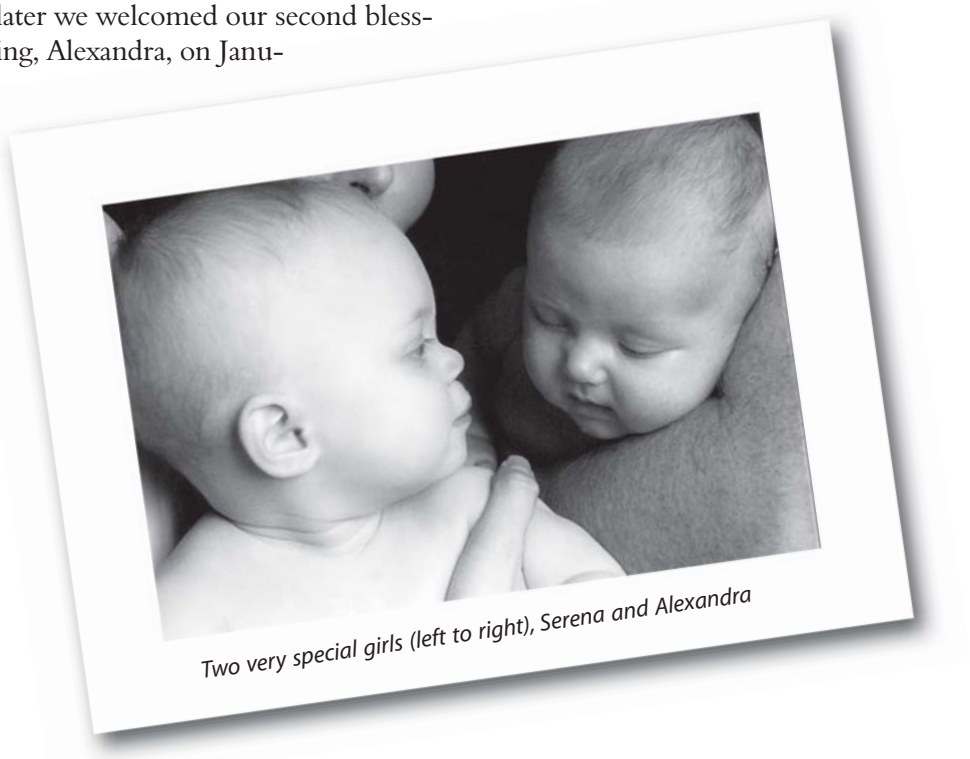
In the exam room, after re-outlining my DES history and the absolute impossibility of pregnancy to the doctor, she hooked me up to a monitor and began moving the probe around. A black blob came into view. "That's your uterus." she said. A tiny star seemed to be flickering in the corner of it. "There." said the doctor enthusiastically. "There's the heartbeat. You must be about six weeks along."

This was no joke — there was a baby growing inside me. Against all odds, I was finally, finally pregnant. I couldn't control the flood of tears rolling down my face and into my ears. A baby was growing inside me. Impossible, but true.

Peter and I traveled to South Africa as planned, bringing home our Serena who was born on July 9th. Six months later we welcomed our second blessing, Alexandra, on January 25. Sometimes I play a game with Alexandra, asking her what took her so long to get here, but I know the answer. She was waiting for us to adopt Serena, her wonderful big sister. If we had gotten pregnant right away we might not have adopted, and I can't imagine our lives without our darling first-born.

Because of Serena, when I read about people who struggle to get pregnant and finally decide to remain child-free instead of adopting, I want to shout "No!" at the page. I want them to know an adopted child is only "an adopted child" until you hold her in your arms. Then she is simply "your child" and you never look back. There is no difference in the abundant love you feel. I want to tell them that if parenthood is what they desire, they will never regret their decision to adopt.

Everything is a little crazy for us now with "the twins." The painful parts of this passage to parenthood have evaporated, as though they never existed at all. Life is funny that way. We love these children so much. We will never forget that our lives have been blessed with two miracles. We were truly touched by the Divine and we couldn't be more grateful. You can't explain joy. DES VOICE



Two very special girls (left to right), Serena and Alexandra

Limit Estrogen Exposure for a Healthier World

By Fran Howell

All of us in the DES community are part of a radical change in the way scientists explore the nature of disease. They used to look at heredity and proclaim that individuals with bad genes were bound to get sick.

But now researchers believe there is nothing clear-cut about it. According to John Peterson Myers, Ph.D., keynote speaker at the recent *Looking Upstream for Environmental Links to Breast Cancer* conference in Cincinnati, scientists are "opening a path to disease prevention" that explores how environmental contaminants change the way genes act. I was lucky enough to attend this conference so I can share what I learned.

Myers, coauthor of *Our Stolen Future* (1996) and founder, CEO and chief scientist of the non-profit group Environmental Health Sciences (www.environmentalhealthnews.org), told the group that this revolution in scientific thinking offers profound opportunities for preventing disease.

He explained that we get genes from our parents, but factors such as stress, environmental contaminants and what we eat actually determine the way genes function. Those factors ultimately determine our health.

So, according to Myers, the more we learn about how toxic compounds effect genes, the better our chances become for preventing disease by limiting our exposure.

Myers says even low amounts of contaminate exposure matter. Years ago scientists knew that high doses of chemicals can kill, but they are now learning that very low doses of toxic chemicals are a force to be reckoned with, too. He says scientists are finding that damage can happen to our bodies at levels we used to think of as acceptable everyday levels for contaminants….in amounts we grew accustomed to calling 'normal' background levels."

Myers uses bisphenol A (BPA) as an example. It is in many plastics, cosmetics, dental sealants, carbonless paper used for receipts at gas station machines, etc. BPA is in places you'd never suspect, and gets into our bodies. According to Myers, it was of no concern to scientists years ago because the levels were low. But new research shows mice exposed prenatally to BPA had altered breast development in females (as reported in Voice 108), and changes in prostate development for males (see Voice 104).

Both BPA and DES are synthetic estrogens. In fact, scientists began working with BPA because they already knew of the medical problems caused by DES. The concern is that while DES is no longer prescribed to pregnant women, BPA use is so prevalent it is difficult to avoid.

As children are born to mothers with detectable BPA levels in their bodies, Myers wonders whether we'll we see increases in breast cancer, prostate cancer, early puberty and obesity, even though the BPA levels are very low. Animal studies are provocative but human effects have yet to be determined. Still, he says, with what he knows, he refuses to drink from plastic water bottles because the plastic has BPA in it. He also doesn't microwave food in plastic containers. Just two small steps one individual can take.

Our experiences with DES stimulated researchers to look at delayed responses to toxic compounds. It came as something of a surprise in the early 1970s that DES exposure before birth could produce cancer years later in teenagers. Myers says scientists are now more routinely looking for fetal origins of adult diseases, and finding evidence of them.

The huge question we face is determining how much evidence we need before taking action to promote health. Myers subscribes to the "precautionary principle," which says we should act to protect health — *if we have evidence of harm* — rather than wait for absolute proof. He points to current epidemics of hormone-related cancers, endometriosis, autoimmune disorders, obesity, and infertility as guideposts showing that action must be taken to decrease risks in our environment.

Myers suggests manufacturers should reconfigure plastics without the DES-like synthetic hormone, BPA. He believes public awareness is needed to press for government regulation and to help consumers make wise purchasing choices.

Because those of us in the DES-exposed community have a heightened awareness of the dangers of excess estrogens in the environment, it stands to reason that we might lead the way in this effort. DES VOICE

DES Action Member Leads Book Discussion

The Women's Rights Information Center of Englewood, New Jersey, held a book discussion of Barbara Seaman's *Greatest Experiment Ever Performed on Women: Exploding the Estrogen Myth.*

Nancy Ferer, a DES Action member and organizer of the event, called the discussion fascinating. She says Dr. Manual Alvarez, chairman, Department of Obstetrics and Gynecology at Hackensack University Medical Center, added his clinical expertise.

He called the book a uniquely helpful way for patients to learn how to question their doctors. It's not something many people do well. Two other participants were doctors who appreciated the book for the same reason and acknowledged that *involved* health consumers make better patients.

The event was tied to Women's Health Week. Copies of the book have been donated to the Health Section of the Women's History Library at the Center. DES VOICE

DES Follow-up Study Update

By Kari Christianson

This summer the National Cancer Institute (NCI) is mailing a new questionnaire to the participants of the DES Follow-up Study. These participants represent the largest cohort of documented DES-exposed people who have been followed over time. Questionnaires have been sent to study cohort members since 1992, when research centers with DES-exposed participants combined with the cohorts established by the NCI beginning in 1974. This important study seeks to identify the on-going health effects of DES exposure and includes an equally important cohort of unexposed people.

Robert Hoover, M.D., Sc.D., and Rebecca Troisi, Sc.D., of the Division of Cancer Epidemiology and Genetics at the National Cancer Institute wrote a letter to study participants which appears on the home page of the DES Follow-up Study web site. In part it says:

"Starting in June of 2006, we will be mailing the next round of questionnaires to those of you participating in the long-term follow-up study. We revised the traditional format of the questionnaires to make them easier to complete, and quicker for us to process so that we can analyze the information collected more efficiently.

"More than 90 percent of you completed a questionnaire during the 2001 mailing, which is a remarkably high rate of response for this type of follow-up. Your continued participation in the study, whether you were exposed to DES or not, is critical to our goal of identifying new health risks and making informed recommendations for improving health care in those exposed to DES.

"Thanks again for your continued support of the NCI Combined DES Cohorts Follow-up Study. We could not do this without you!"

The complete letter, along with new Contact information for the staff of study centers and other updates, can be viewed at www.desfollowupstudy.org. This site is open to all visitors and should be viewed on a regular basis by all of us who are concerned about DES health effects. DES VOICE

Book Notes *from page 8*

knowledges the importance of patient advocates like Ms. Wall, and ends with a paragraph that could have been written about us:

"Many patients I've met over the years have found that becoming an advocate gives them a way to rise above the limits of illness. Whether that means raising funds for research, sharing articles about CFS with friends and health-care providers, or writing to members of Congress to urge increased research funding, the resulting feelings of empowerment can help replace the identity losses that often result from chronic illness. What we know about CFS today has been fueled by activism, and the important questions we have yet to answer warrant our sustained commitment to these efforts…." DES VOICE

DES Daughter Promotes Women's Health Studies with a New Scholarship

Christine Witzel, Ph.D., believes research and social change are the keys to preventing another healthcare tragedy like the DES experience. So she has given her alma mater, the University of Connecticut (UConn), a $25,000 endowment for a scholarship to help students researching women's health issues.

"I'd love for the scholarships to promote new talent who may otherwise not be able to conduct their research," she says. "I hope it helps young people find a career, and for that career to benefit a lot of people."

Witzel was drawn into women's health issues as a DES Daughter and in the 1970s she helped found a DES Action group in Connecticut. Now she is active in the HIV/AIDS movement in the San Francisco Bay area. Witzel strongly believes that good research can be an agent for change.

Christine Witzel Award Fund scholarships will go to UConn students doing innovative women's health research. Their projects must show promise for future funding from a private foundation or a federal agency such as the National Institutes of Health (NIH).

UConn Professor of Social Psychology Jeffrey Fisher acknowledges that it's difficult to find funding for pilot projects. So he says Witzel's support "is an engine that drives preliminary research and is very helpful for those working in the areas of HIV and cancer prevention."

Information about the scholarship is available on line at: http://financialaid.uconn.edu. DES VOICE

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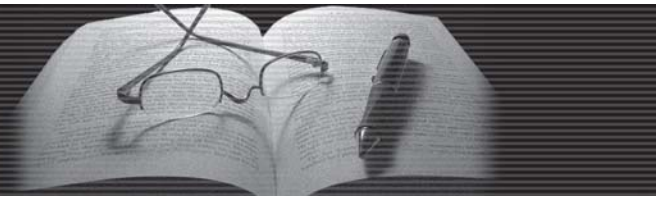

By Pat Cody

Dorothy Wall, *Encounters with the Invisible: Unseen Illness, Controversy, and Chronic Fatigue Syndrome.* Published as part of Medical Humanities Series by Southern Methodist University Press, 2005. 318 pp. $22.50.

We have not found research that links DES exposure with a risk for chronic fatigue syndrome (CFS) or fibromyalgia, but we have had many reports from our members asking about this possibility. Although Ms. Wall is not DES-exposed, we present this review as a first person story of how CFS affects one woman, one family. And how problems of finding physicians who are informed and not dismissive is a struggle for good care and for recognition – concerns that DES daughters certainly have.

Ms. Wall's book weaves her personal story in and out of the account of the long struggle to have CFS recognized – to be named as a distinct disease. She shows why naming is significant. Quoting from a book published in 2000 by Dr. Leonard Jason, "Key decisions regarding the name, case definition, epidemiology and treatment were made…within a sociopolitical context in which CFS was assumed to be a psychologically-based problem."

The author emphasizes that "If you don't believe an illness is genuine, you're not going to allocate funds for research, and as Dr. Leonard Jason says, 'If you underfund (research), you're not going to get the type of science that's needed…In 1984 through '88 a series of mistakes were made that ended up producing a case definition that was problematic, epidemiology that was flawed, and etiological attributions ('it's all in your head') that were inaccurate.' These mistakes, along with a terrible, trivializing name, hampered medical practice and had a profound negative impact on patient experiences for the next two decades."

Living with CFS as she must, Ms. Wall gives a heartfelt description of what surviving a chronic disease entails. Unusual for books of this nature, but very welcome, is an "Afterword" from Nancy Klimas, M.D., of the University of Miami School of Medicine. She ac-

continued on page 7