

Science Confirms What DES Daughters Know From Experience

“Adverse Health Outcomes in Women Exposed In Utero to Diethylstilbestrol,” *The New England Journal of Medicine*, Robert N. Hoover, et al., October 6, 2011; 365: 1304-14.

Reviewed by Kari Christianson

Women exposed before birth to the anti-miscarriage drug diethylstilbestrol (DES), which was prescribed to their mothers primarily from 1938 thru 1971, know all too well of the health problems it inflicted on them as individuals. But an article in the October 6th issue of *The New England Journal of Medicine* provides a comprehensive look at what is known to date of medical problems for DES Daughters as a whole.

According to lead author Robert N. Hoover, M.D., Sc.D., of the National Cancer Institute DES Follow-up Study, researchers can say conclusively that prenatal DES exposure is linked to twelve adverse health problems for DES Daughters. The health problems are: infertility, spontaneous abortion, ectopic pregnancy, second trimester pregnancy loss, preeclampsia, preterm birth, stillbirth, neonatal death, natural menopause prior to the age of 45, cervical intraepithelial neoplasia grade 2 or higher (CIN2+), breast cancer after age 40, and clear cell adenocarcinoma of the vagina and cervix.

For the first time risk assessments also evaluated the presence of vaginal epithelial changes (adenosis) as a bio-

marker of timing and dose of prenatal DES exposure. Researchers documented the dose-response relationship from the records of the DES Daughters in the study, using the presence of adenosis as a measure of the first DES exposure (See page 9 for further information about adenosis).

For most of the twelve adverse health outcomes, the risks were higher still among DES Daughters with vaginal changes, indicating earlier and higher exposure.

As noted by Hoover, most of the twelve health problems are common

in the general population, too. Without the horrific finding 40 years ago of a very rare disease, vaginal clear cell adenocarcinoma, researchers may not have been alerted to the need to study DES-exposed women for other adverse health outcomes, as well.

The DES Follow-up Study has followed the largest cohort of documented DES-exposed people over time. The study, which combined data from three studies initiated in the 1970s, was established in 1992.

Documentation of DES-exposure

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DES Daughters Seek Drug Company Damages for Their Breast Cancer

By Fran Howell

A David vs Goliath encounter is taking place at the Boston Federal Courthouse. Two attorneys representing breast cancer survivors are up against more than 20 lawyers representing a host of drug companies that produced the anti-miscarriage drug diethylstilbestrol (DES).

DES Action USA member Jackie White is one of the 53 plaintiffs who claim their prenatal exposure to DES is why they developed breast cancer. “I joined the lawsuit because drug companies need to be held accountable for

the harm they caused,” says White. “Research shows—and I firmly believe—the DES prescribed to my mother caused my breast cancer.”

Using information collected by the National Cancer Institute DES Follow-up Study, researchers have determined that DES Daughters are about two times more likely to develop breast cancer, after age 40, than unexposed women and the risk increases with age.

Attorney Aaron Levine represents the DES Daughters and acknowledges this is not an easy

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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 Online 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 Online Support Group simply send a blank e-mail to:

DESActionDaughters-subscribe@yahoo.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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MISSION STATEMENT

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Science Confirms What DES Daughters Know *from page 1*

has been one of the key challenges for research studies, but because this cohort of DES-exposed women and men were recruited from health care institutions that had maternal pregnancy records, dose and timing information was available. Additionally, the study of these cohort participants has continued for decades, allowing the researchers to study DES health effects on a population over time.

As Hoover states, "... adverse outcomes continue to occur in women

exposed in utero, and continued monitoring, as is ongoing in this cohort, for established and unexpected adverse outcomes seems prudent."

Of note is that researchers plan to continue following the health of not only DES Daughters, but DES Sons and DES Grandchildren, as well.

Forty years after publication of the first study of an adverse health effect related to prenatal DES exposure, this study clearly states the need for continuing the ongoing research into health experiences of the DES-exposed population. 

DES Daughters Seek Drug Company Damages *from page 1*

lawsuit, because rates of breast cancer rise in all women as they age. "However, the fact that DES was a known carcinogen and known to affect breast tissue and known to cross the placenta since the 1940's, marketing the drug to pregnant women and their babies was unconscionable and negligent, to say the least," he says.


Another DES Action member, Arline MacCormack, found herself fighting for her life at age forty-five after receiving the diagnosis of aggressive breast cancer. She underwent chemotherapy, radiation and multiple surgeries to stem the tide of the disease. "I didn't connect the dots that being a DES Daughter had something to do with my cancer. It was my sister who researched it and made that connection for me."

DES Daughter Cheryl (who asked that her last name not be used), also a DES Action member, felt the case was so important that she flew across the country on opening day to be in the courtroom. Like the others, she was surprised when she first learned of the connection between prenatal DES exposure and her breast cancer diagnosis decades later. "I was shocked when I finally put the puzzle pieces together and realized so many of the medical problems I've dealt with through the years were caused by DES."

The hearing is in recess until late November with final arguments expected in December. Watch the DES Action website (www.desaction.org) and DES Action Facebook Page for

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connection for me."**

details. Attorney Levine is asking individuals from the DES community to attend the hearing and put Faces to the Cases—while also getting a front row seat as this legal drama unfolds.

DES Action member Joanna Katzen is not a plaintiff but understands the importance of being in court to represent the DES community. She attended a session and came away speaking for most DES Daughters. "I sincerely hope this pans out. Only when large corporations anticipate that the cost of deception is higher than acting responsibly will they finally begin to act responsibly and complete proper research before distributing drugs." 

Thank You NCI DES Follow-Up Study Researchers!


By Kari Christianson

At one of the first meetings of the Steering Committee of National Cancer Institute DES Follow-up Study that I attended, Dr. Hoover used the analogy of "panning for gold" to describe DES research. So it's particularly newsworthy when increased risks for twelve adverse health effects linked to DES exposure are listed in one article in the *New England Journal of Medicine*.

With a retrospective study of an exposed population over time, finding the associations to the adverse health effects of DES exposure is a complex process of evaluating and reevaluating the differences between our population and unexposed people. The varied doses and timing of when DES use began in a pregnancy adds to the complexity of the research.

DES Action USA joins with DES-exposed women and men around the world in thanking the dedicated researchers of the DES Follow-up Study. This research not only provides needed information to today's health care providers, but also identifies our past and current DES adverse health and reproductive experiences for our doctors and us.

With perseverance and expertise, the researchers of the DES Follow-up Study have found gold. Thank you!

And, as much as we hope all prenatal and generational adverse health effects have been identified, we're realistic. Panning for gold needs to continue. DES research needs to continue. 

YOUR VOICE

In the last issue of the VOICE we asked for poems written about the DES experience and poems came rolling in! To quote member Paula Panzarella, "Through poetry we share ourselves close to the heart. It is exhilaratingly liberating to be able to put words and feelings in print. The very act of being able to express oneself brings comfort. When we find our voice we find our strength." So true! We now proudly share this expressive and poignant collection of DES poetry!

AN ODE TO ELI LILLY

Eli Lilly caused such fear
But who among them shed a tear?
Sadness and pain, guilt and shame
Mothers so worried, taking the blame
Corporate suits mind the bottom line
But to our suffering they are blind
Healing for us comes hard and slow
Working together we're stronger we know
So keep your billions in ill-gotten gains
We look in the mirror – can you say the same?
—Martha Cody

ANGUISH OF A DES MOTHER

The year was 1963 when Eli Lilly poisoned me and
My innocent baby that grew in my womb
I trusted the doctors and swallowed the pills
Naive and ignorant of all the ills and distress
Evoked upon mothers who took DES
It took five years for me to discover
The ugly truth Lilly hid under cover
The next eight years watching her grow
Brought great joy along with emotional strife
Soon, she would need to know
"I" took DES and it ravaged "her" life
I prayed for courage to face what I must
I hoped I would never lose my daughter's trust
Will she understand, will she ever forgive
I took DES so that she would live
How will I explain when she asks "why me"
Will she comprehend the rapacious greed of
Eli Lilly's preying on maternal need
Will she know how much I share her pain
As doctors probe her again and again
Her miscarriages and tumors and operations
Ended all hope for her reproduction
Our DNA and her maternal quest ended when I took DES
—Chris Vanselous

EXOGENY—

I am crystallizing and precarious.
Materializing as form where water lets me.
Sonic, I'm vibration.
Dark undulating universe.
This is my mother, who has been poisoned for me.
—Sarah Fox (from *Mother Substance*, a long form DES poem)

MOM'S GUILT

Mom's guilt is buried beside her.
She died still waiting for apology.
Grandkids relieved her guilt, in part.
Pat's right: turn anger to action.
—Litsa Varonis

IT WAS TOO EARLY

It was supposed to be April
But she was here in December
It was too early, way too early
Even for the latest technology...
The shock of birth
Turned into the shock of death
And so, I look enviously at times
At families with four children...
She was a tiny little girl
Resembling on a much smaller scale her older sister
But her eyes would never see
Her hands would never clasp mine
She never got to drink my milk
Or smile
But for a drug
Known to cause this
She might have been twenty-five
She might have been...alive...
—Joyce Solomon

continued next page

PASSING THROUGH THE DOOR

Passing through the door to
Grow big & tall.
Never to grapple for the undertow;
May make you tumble and fall.
Awaking to a shadow's edge
shall never harden the heart.
Bellowing under the sky above,
Proves stifling doesn't gather
the dreams of hope encourage one
passing through that door.

Passing through the door
coming to the other side.
Witnessing the sine wing figure
of all dreams passed by!
Ebbbed in a field, clusters hanging fro.
Putting souls to sleep amidst
the haunting shadows that fall.
It by passes, yet arises to the heart's center.
The loose arrows flying high,
Slowly passes through the door!

—Joanne G. Snyder-Haney

DES BABY

Haunted by a past preceding awareness
Pills ingested by my mother
coursing through her womb
potent as a time bomb ticking.
Each attendant at that birth
including the Mephistophelean dispenser
disguised in robes of white
overlooked internal construction
genital lips announced a normal girl
strew the pink confetti.

Years slid by before a magazine
exposed misshapen interiors
satin walls ridged and creviced
abnormal cells bidding time
I cried at 24
invaded by a microscope
eyes too powerful to lie
focused on the hidden birthmark
a freak of nature designed by man.
I cried at 30 waiting for a biopsy
undifferentiated from the rest
At 35 awaiting my daughter's birth, I chuckled . . .
a raw intern's panic at livered tissue
How predictable!
They say none of us are old enough to know
what menopause will bring

or if our daughters carry
the same mantle of distortion
And so I wait.

—Mary Damer

TWO SISTERS

It took a while for Mom
to leave her ranch abode,
though Indians were encouraged to relocate
and so untie the mold.
Her sister dear and mommy
eloped to urban life
They never realized DES
would put them under that knife.
Together scalped by doctor's visions
of how to 'take' their fears,
The thing that frightened grandmother
They knew through all her tears.
"Do anything to keep that child"
ran constant in their hearts
So pleasing mom in her absence
helped them off to a modern start.
One chose to put it forth, there had been a small mistake,
the other swore to secrecy left in her soul to bake:
we are the aftermath
with questions bright anew
How can we return to native life
the one we never knew?

—Sarah Mix

DIETHYLSTILBESTROL, ALSO KNOWN AS DES, IS HARMLESS, THEY SAY

For the Food and Drug Administration that approved it
All the doctors who prescribed it
All the pharmaceutical companies that produced it
All the stockholders who made money from its sale
All the farmers who put it in their animals' feed
And all the politicians who were bribed to keep it from be-
ing banned

This Poem Is For You

"Proof?" You want "PROOF?"

Let me come to your board meetings

I'll show you "proof"

I'll get up on the table

Pull my pants down

S p r e a d m y l e g s w i d e

And show you "proof"

Many doctors have said

I have a cervix

That's
Unique
And
Unforgettable

—Paula Panzarella—DES Daughter #2,487,673

MY MOTHER, WHO COULD NOT

I was a shy fifteen when she told me,
“Des baby, Diethylstilbestrol.”

What did those dark secret words mean to me?
It was 1971 and I had a crush on James Taylor.

She took me to her OBGYN
the tall grave doctor who prescribed her pills,

only 80 lbs, not yet menstruating,
my legs wide open for the steel speculum.

They consulted; I went invisible,
my nurse mother and the tall grave doctor;
that was when her shame began, eyes downcast,
anger at the facts, anger turned to silence.

I did everything wrong, went on the pill,
that's what girls did, though I had never menstruated.

Years later, years, a new doctor explained,
“tipped, flattened uterus, colposcopy,
potential cancer, clear cell adenocarcinoma,
unlikely you'll have full term pregnancies.”

My mother, still ashamed would not talk to me.
Diethylstilbestrol rolled off my tongue.

One of the lucky ones, I had two children,
Healthy babies; mom's broken promise.

DES, a promise for a tipped and
flattened uterus, malformed urethra,
lifelong urinary tract problems,
immune deficiencies, Adenomyosis
radical hysterectomy, fear...

Four months before she died of breast cancer,
she apologized for her angry silence.

She was seventy; shamed by her own belief—
“pills could cure everything,” shame, still heavy
as love, left her weak with a desire
to be forgiven; I was forty-three.

—Susan Cohen

COMPOUNDED MATHS OF DES

evaluate:

twists of wonder drug hype
that sap the tiny fetal system
in cancerous dumps of D-E-S
inert toxic
in utero in mother-love

add:

calm doctor-words to soothe
the fray of maternal nerves -
candy-clatter spills of D-E-S pills
to hide kerching of dividends

subtract post-birth:

wombs of babies and their bits *down there*
(lost in cancer's lust)
records
(lost in rush or floods or flame)
voices
(lost in D-E-S hush)

then multiply:

the repeating clouds of cancer thoughts
the shuns intercepting rights for care
the power of wonder drug cravings

equals:

an imbalanced equation—
the women who weep
while people in obtusity
sweep dust of D-E-S under carpets

—Carol Devine

WE TRY TO FILL IN THE FORMS

At the new doctor's office,
she writes her family history:
father—died, Hodgkin's disease – 1971
mother – died, breast cancer – 1998
sister—died, ovarian cancer – 2000

There is no box for DES.

Our practice deleted DES from our intake forms.
Those patients are no long around.

We,
she thinks,
are still here.

—Susan Cohen

News Media Takes Notice of DES

Can you feel the excitement? Stories about DES are everywhere! All across the country people are reading about DES and sharing what they've learned with others. Word is spreading.

What happened quickly in October was actually a long time in the making. Robert Hoover and his team at the National Cancer Institute have been studying DES exposure for decades. During the past years, they compiled a long list of health impacts for DES Daughters and planned to submit this important study to a national medical journal.

They hit the jackpot when the highly regarded *New England Journal of Medicine* (NEJM) published their article, *Adverse Health Outcomes in Women Exposed in Utero to Diethylstilbestrol* in the October 6, 2011, issue.

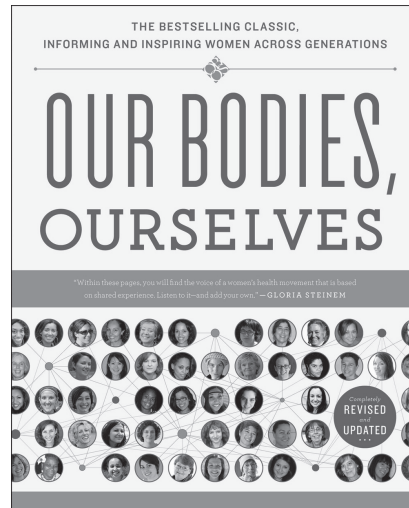
Doing our part, DES Action USA assembled a terrific team of DES Daughters who agreed to be interviewed about what they've been through as a result of their DES exposure. We were ready with the names and press packets for reporters who read the NEJM article and wanted to follow up with their own stories.

The preparation paid off and reporters responded. DES news coverage turned up not only across the U.S. but worldwide as well. It all worked as planned, and DES Action USA has been busy answering requests for DES information ever since.

All in all October was an amazing month. The NEJM article reached doctors who needed to be reminded that their DES patients have valid health concerns. And DES awareness spiked in the general public as word got out—again—about DES exposure.

DES VOICE

"Our Bodies, Ourselves" Celebrates 40 Years and Contains Updated DES Information



Our Bodies, Ourselves, The Boston Women's Health Book Collection, 2011, \$26.00.

By Kari Christianson

Our Bodies, Ourselves (OBOS) has always been my go-to health manual. It still is—after 40 years. The 1975 edition was the first that I remember owning. But I had read and reread my friends' earlier editions, searching for information about DES exposure, as well as a multitude of women's health and sexuality issues. Perhaps because it was the first book that had a section for DES Daughters, OBOS offered me a roadmap on how to be an activist, that I could feel fear about my personal health situation as a DES Daughter and still have a strong voice for others and myself.

In October OBOS celebrated its 40th year with a new edition and a symposium. I was lucky enough to be able to attend and represent DES Action USA, which contributed the updated section on health effects from prenatal and generational exposure to diethylstilbestrol.

"*Our Bodies, Ourselves* has always been more than just a book. It is emblematic of a women's health movement committed to principles of feminism as well as social justice, economic, and racial justice for all." (Excerpt from the OBOS 40th Anniversary Welcome in the Symposium program.)

OBOS was never "only" a book; it is a non-profit organization that is and always has been a voice for women's issues around the world. International partners gave presentations during the gathering, citing examples of how the book influences health care systems and social justice activities in their countries.

Thank you, OBOS! And congratulations on 40 years of giving us the information we need about women's health, including DES exposure published in the first edition and every edition since.

Our Bodies, Ourselves 2011 is available from Amazon.com and Powells.com, as well in bookstores. Learn more about the book at www.ourbodiesourselves.org.



DES Action's Kari Christianson with *Our Bodies, Ourselves* Executive Director Judy Norsigian

DES VOICE

Significant Honor Bestowed On French DES Activist!

Anne Levadou worked as an accountant in a shoe factory before becoming a nurse. But it was the DES cancer diagnosed in her daughter, Veronique, that changed her life. Late last month Levadou was bestowed an official distinction by the French Republic, via the Ministry of Health. She was awarded the *National Order of Merit* for her efforts on behalf of DES-exposed individuals in France.

In helping create and becoming president of Reseau D.E.S. France, Levadou's motto is, "Live with and not give in to the consequences of DES."

Co-Founder of DES Action USA, Pat Cody, an activist and DES Mother just like Levadou, always demurred personal honors, saying it takes many individuals and thousands of voices to accomplish change. For those of us who learned about DES because of these two amazing women, we know their leadership made the difference by



combining rare abilities of drawing people together, advocating articulately and focusing attention on the DES health disaster, along with offering support and words of wisdom, as a mother does.

DES Action USA celebrates and salutes our sister and colleague in DES health education and outreach. And we thank the government of France for recognizing Levadou's unique and everlasting contribution to the health and education of DES-exposed individuals throughout the world by presenting the *National Order of Merit* to her.

DES VOICE

What Is Vaginal Adenosis?

Vaginal adenosis is a condition found primarily in DES Daughters when a type of tissue develops on the surface of the vagina that is not generally found there in unexposed women. Because these cells can be (but usually are not) a precursor to cancer, they should be carefully monitored.

A layer of flat cells called squamous cells normally lines the vagina. But DES Daughters often have sections of the vagina lined with glandular cells most often found lining the uterus, fallopian tubes and cervix. When these glandular cells are located in the vagina, they are called adenosis. While this is completely normal tissue in the body, it is in the wrong place.

Blame these extra glandular cells for secreting the profuse vaginal discharge many DES Daughters have experienced.

According to the latest research, there appears to be a dose-response relationship regarding adenosis. When there is adenosis, often exhibited by excessive amounts of mucous discharge, it indicates the prenatal DES dose was high and early in the pregnancy.

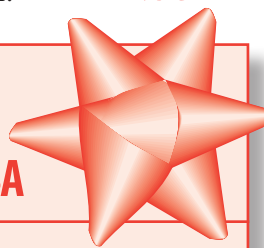
Many DES Daughters experience a lessening of vaginal discharge as they age. This has raised the question as to whether adenosis "resolves" itself or whether it is simply covered over by "normal" squamous tissue with the glandular cells lurking underneath.

The "covered over" hypothesis is hugely important because adenosis is where the DES associated cancer, clear cell adenocarcinoma (CCA), develops. If those glandular cells exist underneath a new top layer of "normal" tissue on the vagina surface, then cancers in that tissue could be missed.

That explains why vaginal palpation (or feeling for unusual lumps under the vagina wall) is such an important part of the annual DES Daughter Pap/pelvic exam. Luckily, CCA is rare, even in DES Daughters. But at this point no upper age limit has been identified, which is why the recommendation is for DES Daughters to have annual Pap/pelvic screenings throughout their lives with thorough vaginal palpation.

DES VOICE

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DES ACTION USA HEALTH HISTORY QUESTIONNAIRES

Your Chance to Participate Coming Soon!

One of the most frequent questions to DES Action USA is, "Are there any DES research studies I can join?" Our answer is always the same. The NCI DES Follow-up Study is closed to new participants, but DES Action does provide to the researchers an anecdotal list of health experiences we hear about. That information is of interest to the researchers who want to know of the actual health problems being experienced in the DES community.

DES Action has joined with epidemiologist Deborah Wingard, Ph.D., Professor in the Department of Family & Preventive Medicine at the University of California San Diego, and her students in developing a health history questionnaire.

This isn't the first time Dr. Wingard and DES Action have worked on a DES health questionnaire. In 1984 a similar one was included in the VOICE. Over 1700 people completed and returned it.

The new questionnaire will gather self-reported information. While not every adverse health experience is related to DES exposure, reporting our health experiences may provide clues for researchers with the DES Follow-up Study, and others, studying DES health effects.

The questionnaire will be included in the next issue of the VOICE, due in March 2012. We hope to make it available via online resources in addition to the newsletter, but that is still in the planning stages.

This is an exciting opportunity for all of our voices to be heard regarding health problems experienced by those exposed to DES. And it is a significant project supported by DES Action USA membership!



DES VOICE