

# The DES Tragedy Intergenerational Impact





# Diethylstilbestrol/DES



- First Synthetic Estrogen
- Developed in 1932 to relieve menopause symptoms
- Caused tumors in rats
- 1947 re-purposed as a preventative for miscarriages



# DES: Assumptions About Efficacy



Assumption:

Estrogen = good

More estrogen = better



# DES To Prevent Miscarriage

*"Really?"*

Yes...

**desPLEX<sup>®</sup>**

to prevent ABORTION, MISCARRIAGE and  
PREMATURE LABOR

recommended for routine prophylaxis  
in ALL pregnancies...

96 per cent live delivery with desPLEX

in one series of 1200 patients<sup>4</sup>—  
— bigger and stronger babies, too.<sup>4,5</sup>

No gastric or other side effects with desPLEX

— in either high or low dosage<sup>3,4,5</sup>

(Each desPLEX tablet starts with 25 mg. of diethylstilbestrol, U.S.P., which is then ultramicrotized to smooth and accelerate absorption and activity. A portion of this ultramicrotized diethylstilbestrol is even included in the tablet coating to assure prompt help in emergencies. desPLEX tablets also contain vitamin C and certain members of the vitamin B complex to aid detoxification in pregnancy and the effectuation of estrogen.)

For further data and a generous  
trial supply of desPLEX, write to:  
Medical Director

#### REFERENCES

1. Sprankle, E. M., et al. *Am. J. Obst. & Gynec.* 63:1290, 1953.
2. Cramer, L., and Kellum, R. J. *Obst. & Gynec.* 50:2123, 1953.
3. Karmali, M. J. *South. M. J.* 45:1166, 1952.
4. Patis, E. A. *Obst. Gynec.* 67:527, 1954; *Am. J. Surg.* 87:95, 1954.
5. Rapp, J. W. *J. Amer. Med. Ass.* 42:10, 1951; 43:222, 1953.

**GRANT CHEMICAL COMPANY, INC.,** Brooklyn 26, N.Y.

- Supporting research weak
- 40+ drug companies, Eli Lilly
- Equivalent to 500,000 low dose contraceptive pills



# 1953: DES Proven Ineffective



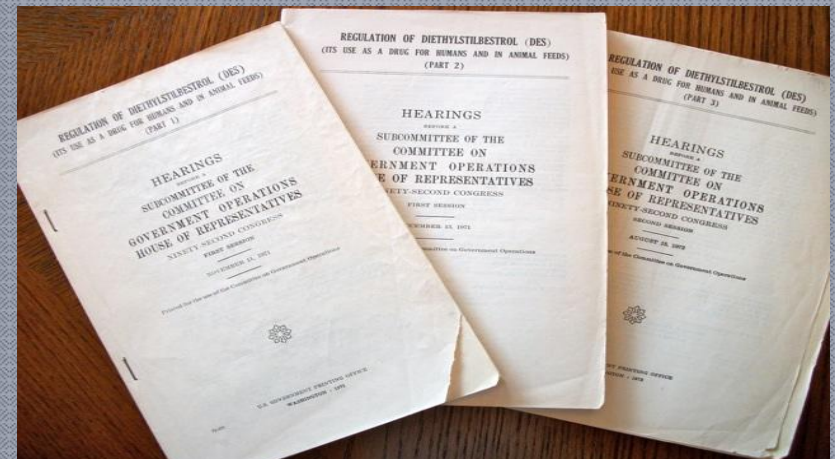
- Double blind study with hundreds of subjects
- FDA takes no action
- Sales remain high -
  - Belief in “wonder drugs”
  - Psychological push to have children



# 1971 Herbst Study



- 1966 CCA diagnosed in a 15-year old girl
- April 22, 1971 article linked DES exposure to CCA
- By November 1971 more than 650 teen girls with CCA
- FDA takes no action





# DES Groups Spring Up



- Planned Parenthood, Coalition for the Medical Rights for Women, provide training and support
- Local DES Action orgs  
DES Watch, DES Action Project, DES Ed Group, DES Cancer Network, etc.
- Early success with states funding education programs



# DES Action USA Formed



- Individual orgs agree to come together
- 1978 DES Action USA independent state chapters
- Berkeley “lead” chapter, Pat Cody leads, publishes VOICE newsletter
- HEW recommends Drs. alert all DES patients



# What Had to Happen First?



1. Identify DES-Exposed
2. Research
3. Legal Issues



# 1.) Identify DES-exposed



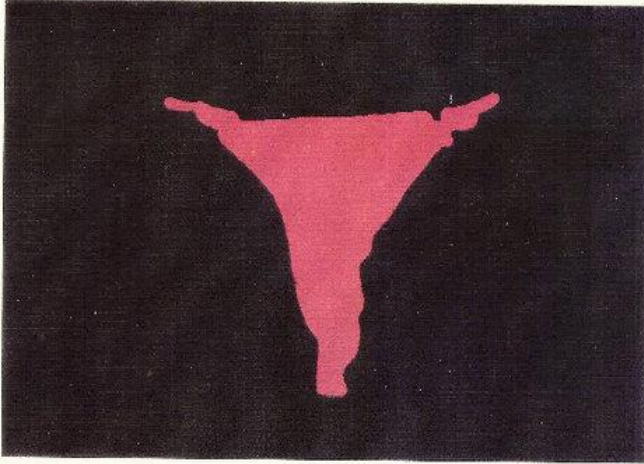
- Damages not apparent until fertility years, 15- 25 years from initial exposure
- Medical records destroyed, doctors deny
- Massive ethical violations
- 5,000,000 - 10,000,000 mothers exposed



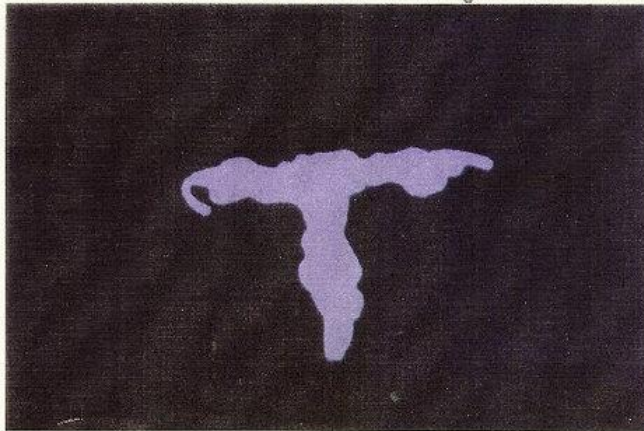
## 2.) Research



Normal uterus



T-shaped uterus of a DES daughter



- What was known and what was to be learned?
- CCA and infertility were first signs, what might happen next?
- Who would conduct research? Who would pay?



### 3.) Legal Issues



British DES Pill Label

- Who is at fault, who will pay damages?
- Statute of Limitations
- Will insurance companies cover DES damages?



# DES Action USA Objectives



- Education
- Advocacy
- Research





# Education: Outreach Campaign



- Campaign theme: Ask Your Mother, Tell Your Daughter, Ask Your Doctor
- National press - PSAs on national TV, newspaper and mag articles
- By lobbying got states to legislate ed programs and DES screening centers
- 1983 (April) 1st national DES Awareness Week held in 29 states
- 1985 President Reagan proclaims National DES Awareness Week held April 21-27, 1985; currently inactive



# Advocacy: Legal Advances



- Lobbied and got laws prohibiting insurance discrimination against those exposed to DES
- Change statute of limitations laws - NYS first
- 2000 - The FDA withdrew approval of DES - no longer be prescribed for human use



# Research & Physician Education



- Consumer-physician programs to increase cooperation for improving care, and providing support and information for DES Daughters.
- Publishes many guides for doctors and the DES-exposed.
- Sponsored international gatherings of DES researchers
- 1986 - 1st DES Action Health History Survey released – higher occurrences of arthritis, asthma and Lupus than in the general population. Anecdotal but guides NIH research



# What We Know Now



DES was the first endocrine disruptor  
reproductive  
neurological  
immune

Maternal estrogen does not cross the placental barrier, DES  
does

Affected the mother, child and now 3rd generation



# What We Know Now



- Cancer: breast, vaginal CCA, testicular, prostate
- Reproductive: Structural changes of reproductive organs; infertility; ectopic pregnancy; miscarriage; preterm labor; preeclampsia, fibroids, endometriosis, late menses and early menopause
- Cardiovascular disease, diabetes, high cholesterol, hypertension, osteoporosis
- Transgender and androgeny
- Emotional impacts: trauma, depression



# DES Action's Future



Identify, educate, empower and advocate



## Challenges

- exposure confusion, how do you know it's DES?
- single disease support groups



# Why I Am A Patient Advocate



Diethylstilbestrol: The  
1st endocrine disruptor,  
wreaking health havoc  
on 3 generations

- DES-like disasters are happening today
  - The FDA “fast-tracking” policy weakens testing requirements
  - No long-term testing on drugs before approval



# MedShadow Foundation



- All drugs have side effects
  - And not all long-term effects are known
- Benefits of drugs are not guaranteed
- To make an informed decision on your own health care
  - Understand the possible benefits and the known risks





# Thank you!



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