



A Focus On Diethylstilbestrol

SPRING 2011 #128

DES Was Linked To Cancer Forty Years Ago

By Fran Howell, DES Action Executive Director

Sometimes the confluence of events allows for the possibility of a miracle — but only if individuals recognize the signs and act on them. Such was the case 40 years ago in Boston.

First came the strange occurrence noted by gynecologic oncologists at Massachusetts General Hospital. Seven young girls from around New England were referred there for treatment of a rare vaginal cancer seen before only in much older women. Dr. Arthur Herbst and his colleagues took note and in a 1970 article in the journal, *Cancer*, they wrote about it but could offer no explanation as to what was going on. Then came word of an eighth clear cell adenocarcinoma (CCA) case being treated at another Boston hospital. This was nearly unheard of.

Finally, the mother of one of the girls provided a clue. Her simple question was whether the anti-miscarriage drug she had been prescribed while pregnant could have played a part in her daughter's cancer more than a decade later.

It seemed improbable, but with little else to go on the doctors followed up. To their enormous surprise, medical records confirmed that seven of the eight mothers had something in common – they had been prescribed DES while pregnant! None of the unexposed female children born in the same hospitals at the same time developed vaginal cancer.

Significance of the Finding

Dr. Herbst's April 22, 1971, *New England Journal of Medicine* article about the discovery solved the cancer mystery. DES was associated with these cancers. Prior to this, doctors and researchers had not considered the possibility of adult onset of disease from prenatal exposures. Now, forty years later, it is something we hear of frequently, but at the time this was a revolutionary concept.

The *Journal* has strict rules about leaking article information until it is published. Dr. Herbst recalls the fright he got shortly before publication, when CBS News correspondent Daniel Schorr called his office. A news story right then about the association between DES and cancer might kill the

journal article. With much trepidation Dr. Herbst says he took the call, only to find out that one of the reporter's relatives was in Boston and "wanted me to see her as a patient." It was not a story about DES. But Dr. Herbst knew there would be plenty once the article came out.

He and his wife spent a long weekend in the country before the article was published, and then his life and career changed forever. Dr. Herbst remembers spending significant time with reporters to help them fully understand the findings, so they could write their stories without sensationalizing them. "Information had to get out, but I felt a responsibility to avoid having it cause hysteria," he says.

While Dr. Herbst explained that prenatal DES exposure was associated with cancer, he made it as clear as he could that not every DES Daughter would get vaginal cancer. And most did not. But Dr. Herbst stressed the need for health screenings of DES Daughters. He takes comfort in knowing that the national DES discussion he helped start resulted in the finding of tumors in some young women who otherwise would not have been checked. Many were discovered early enough for successful treatment. Dr. Herbst is also aware that the DES discovery pushed medical research forward in a new direction. Current studies of prenatal environmental disruptor exposures harken back to what was first learned about DES. What happens in the womb matters.

The fact that a cluster of DES-related cancers all turned up at the same time in Boston in a group of young girls who should not otherwise have been stricken by the disease is, as Dr. Herbst describes it, "very surprising and unusual." He acknowledges that without fate bringing everyone together as it did, the dangers of DES exposure might not have been uncovered in 1971, or potentially, ever.