

RSM 00052

Meeting Report

DES: a drug with consequences for healthy policy

Dublin, Ireland, 14 September 1990

Elsewhere in this issue of the *Journal*, Henry Lynch and his colleagues from Omaha, Nebraska provide a comprehensive account of the medical and legal facets of the diethylstilbestrol (DES) story. How widespread the harm done by this drug will ultimately prove to be we still do not know, for in many parts of the world anyone seeking the answer is likely to be met with a shrug of the shoulder and the bland assurance that “it didn’t happen here”. That any part of the epidemiological map of DES injury has been filled in at all is very much to the credit of a small but determined group of women – the DES Action Groups – composed largely of mothers who themselves took the drug during pregnancy and daughters who were thereby exposed to it.

The campaign to track down DES mothers and daughters has now swung into Ireland with the holding of the First International DES Symposium on September 14th. Uncovering the history of DES in Ireland has already encountered obstacles which have become familiar elsewhere. As Frances Fitzgerald, Chairwoman of Ireland’s Council for the Status of Women, told the meeting, the Department of Health found “that there was not much that they could do because of the time which had elapsed since DES had been used in Ireland”; even the names under which it may have been prescribed seemed to have been forgotten. The Minister of Health spoke in Parliament of the virtual impossibility of tracing the female offspring of women who had taken DES and expressed the now familiar concern of the medical establishment that the topic should be approached cautiously to avoid seeding undue fear of cancer. To their credit, the College of General Practitioners did give the issue publicity, and the Irish Cancer Society provided some travel funds.

In fact one of the most important achievements of the DES Action Groups is to have achieved publicity and to have traced very many women exposed in utero to the drug without causing panic; sensible and well-advised, the Groups have put the provision of sound counselling in the forefront of their activities. A woman with a history of DES exposure needs to know precisely what the risks are and to enter a programme of routine screening so that changes which are present or do develop can be detected at an early stage before they become serious; counselling is also called for as regards the way in which pregnancy and childbirth should be handled. That approach causes very few indeed to experience undue fear; on the contrary, for the great majority it clearly allays fears, provides positive support, and ultimately it will also save many lives. If, as one medical participant at the meeting somewhat temerously suggested, this amounts to seeding “hysteria”, one had better redefine hysteria. But at least that critic came to the meeting; the essential problem within the medical community, and particularly those who were in practice when DES was still actively in use, is that so many even today choose to shrug their shoulders, to deny, or to forget.

As Pat Cody, the pioneer of the DES movement in the United States, was able to report, the movement has succeeded in finding physicians who will work closely with it, including researchers, academic staff of university medical centers and workers in public health departments. The U.S. movement has a Medical Advisory Board which reviews its publica-

tions and which itself benefits from the movement's findings and research potential. Happily, America's National Cancer Institute has been persuaded to continue its support to that research; with some evidence that problems could extend into the third generation – a possibility which at the very least deserves to be examined and if possible excluded – that research will have to go on for a long time to come.

Where one is dealing with a global epidemic it is fair to expect something of International agencies in undertaking and financing the work which has to be done. To its credit, the World Health Organization was heavily persuasive in its contacts with the funding agencies in the U.S.A.; and the W.H.O.-linked International Agency on Research on Cancer is about to launch a monograph on the DES situation. In May 1989, too, the European Parliament adopted a resolution inviting the European Commission to investigate the issue, to set up a central registry for vaginal cancer and to initiate an information campaign for the public. As Mary Banotti, an Irish member of the European Parliament pointed out, however, to the Dublin meeting, it may prove difficult to persuade the Committee of Cancer experts of the "Europe against Cancer Programme" to allocate the DES issue high priority, since DES cancers are comparatively rare. That is one of the paradoxical stumbling blocks which one encounters; society likes to compartmentalize its problems according to past experience, and DES is not exclusively a cancer problem; it is also a gynaecological and a genetic issue and it is therefore all too easy for one group of experts to leave matters to another. Whether a future European drug regulatory body will tackle things any better remains a matter for speculation; Ms Banotti voiced the concern of some consumers that it may lower standards in drug safety rather than improving them.

After a generation and more, a tragic aspect of DES is that the injury which it caused was never counterbalanced by any evident benefit. As Simone Buitendijk, another DES pioneer who has become a distinguished medical epidemiologist, reminded those present in Dublin, we are not much further along the road to the proper treatment and prevention of miscarriage than we were when DES ran its reckless path. What we may have learnt is to adopt a more critical view to the use of drugs – any drugs – in pregnancy.

For the record: much of the international work undertaken in the field is co-ordinated by DES Action, Maliesingel 46, 3581 BM Utrecht, The Netherlands; telephone 030-340472. It is a cause which deserves very wide support.

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