

US launches new clinical trials database

Fred Charatan *Florida*

The US National Institutes of Health and the Food and Drug Administration have jointly set up a database of all US clinical trials for serious illnesses.

The action is a result of the Food and Drug Modernization Act of 1997, which required the Department of Health and Human Services to establish a registry of the clinical trials being conducted for both the governmental and private sectors.

"This is the single place you can go where the most important information, we hope, will be available to everybody," said

Dr Donald Lindberg of the National Library of Medicine, the largest medical library in the world, which is running the registry.

The website contains information on about 4000 studies being conducted at 47000 sites nationwide, most of which are sponsored by the National Institutes of Health or universities. More studies, particularly trials run by drug companies, will likely be added.

Access to the new registry is free (<http://clinicaltrials.gov>), and the registry will be regularly updated. An introductory statement reads: "This federally sponsored database is designed to be the most comprehensive central listing of clinical studies sponsored by the National Institutes of Health, other federal agencies, the pharmaceutical industry and non-profit organisations."

"Users are not asked to provide personal information, nor will they be sent unsolicited material."

A freephone number for the database is planned for 2001. The website also provides information for people considering participating in a trial. It has a list of 20 frequently asked questions and answers, including: what is a clinical trial; what is a protocol; what is informed consent; what is a control or control group; what protections are there for participants?

The website also contains information on understanding clinical trials from a patient's perspective, by Patty Delaney, a 10 year survivor of Hodgkin's disease and a member of the Food and Drug Administration's cancer liaison programme in the Office of Special Health Issues. □

India eradicates guinea worm disease

Rohit Sharma *Mumbai, India*

India and other countries of the South East Asian region have officially been certified as free of guinea worm disease (dracunculiasis) by the World Health Organization (WHO). This is the second disease to be eradicated from the region—smallpox was the first.

The 4th International Commission for Certification of Dracunculiasis Eradication gave its clearance mainly on the basis of the report of its three member certification team, which visited India in November 1999 and investigated 62 villages in five states where the disease had been endemic.

Guinea worm disease is thought to have existed in India for several thousand years. In 1947 India was estimated to have some 25 million cases. When the Indian government launched its national guinea worm eradication programme in 1983-4, nearly 40 000 cases occurred annually in more than 12 000 villages scattered over seven states. Sustained campaigns were launched at grass-roots levels by agencies such as Unicef and the WHO, with government collaboration.

Banwari Lal, a 25 year old man from the Jodhpur district in Rajasthan, was India's last reported case of guinea worm disease, in July 1996.

The programme has been evaluated seven times by independent experts. "This is a remarkable achievement made possible by active intersectoral collaboration between the key departments of health, water supply, and rural development," said Henk van Norden, the coordinator of Water Supply—a division of Unicef—which played a crucial part in the eradication of guinea worm disease.

The zeal displayed by workers from village level to the top leadership played a critical part in this success story, he said.

Although guinea worm disease has been eradicated from India, it still exists in a dozen countries in sub-Saharan Africa, with Sudan having the most cases. □

Patients must disclose infectious diseases, Israeli doctors say

Judy Siegel-Itzkovich *Jerusalem*

The Israel Medical Association has called for a law to be passed requiring all patients to tell doctors who treat them about any infectious disease they have.

The call follows a week long brouhaha that erupted when a Hebrew language daily newspaper, *Ha'aretz*, published the fact that the internationally known pop star Ofra Haza had died of complications of AIDS.

The refusal by Ms Haza and her family to reveal that she was infected with HIV "magnified the stigma of AIDS and took us back 20 years by demonising the disease," said Professor Zvi Bentwich, head of the AIDS clinic at Kaplan Hospital in Rehovot.

Professor Bentwich said that Ms Haza, who came from a religious Jewish family of Yemenite origin, "literally died from shame." Having preferred to take protease inhibitors from a private physician rather than get treatment at a hospital AIDS clinic, Ms Haza developed complications instead of living with AIDS as a chronic disease.

The reason for her admission to hospital had been concealed by newspapers because of the two year old "patients' rights"

law, which bars the release and publication of personal medical information without permission from the individual or the family.

The 41 year old singer, who was well known in Europe, walked into Sheba Hospital and asked that no details be released to the public about her condition or illness. She quickly collapsed, and many of her bodily systems failed. The accident and emergency staff had not been briefed about her medical history by her personal physician.

No cause of death was announced by the hospital when she died. Rumours spread,

and *Ha'aretz* decided to publish the cause, quoting officials anonymously.

After staff at Sheba Hospital complained to the press that their lack of information about Ms Haza's condition might have put them in danger, the Israel Medical Association's chairman, Dr Yoram Blachar, demanded to know whether Ms Haza or her family had informed hospital doctors that she was infected with HIV. If not, he said, they had exposed medical workers to needless risk.

But Dr Zvi Ben-Yishai, head of the health ministry's AIDS steering committee, dismissed the association's queries. "All hospitals and their staff have standing orders to treat any patient as potentially being a carrier of AIDS or another infectious disease." □



Israelis mourn the singer Ofra Haza, who kept her AIDS a secret