US launches new clinical trials database

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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 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 47,000 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 organizations. Users are not asked to provide personal information, nor will they be sent unsolicited material."

A free phone 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 program in the Office of Special Health Issues.