Birth Defects Information Service begins operations at T-NEMC

A computer-based information network containing all that is known about some 1400 specific birth defects to aid pediatricians across the nation in diagnoses has begun operation as the Center for Birth Defects Information Services (CBDIS) at T-NEMC. It was funded by the National Foundation-March of Dimes and developed in conjunction with MIT and T-NEMC.

Dr. Sidney S. Gellis, chief of pediatrics at T-NEMC and one of the three members of the CBDIS management team, says that the computer system will not only sort through all the possibilities and help the doctor with the appropriate treatment, but also eventually will serve as an early warning network to spot clusters of birth defects that might be environmentally triggered.

"Another thalidomide disaster would be prevented," said Dr. Gellis, referring to the tragic epidemic of limbless babies as a result of the use of a tranquilizer in the 1960s.

"Birth defects are becoming more and more important as a part of pediatric practice," said Dr. Gellis. "Some are so rare that a doctor may never see more than one in his entire career, and clearly, no one doctor can carry enough information around in his head to know what to do when a rare birth defect turns up." The computer, he continued, will assist the physician in providing the appropriate treatment and counseling.

The computer's collection of data was gathered by 436 physicians from 22 countries, and new genetic and birth defects data are continually being entered. The project was coordinated by Dr. Gellis, Daniel Bergsma, M.D., chairman of the

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CBDIS management committee; and John Donovan, Ph.D., associate professor of management science, MIT, secretary of the CBDIS management committee and acting director of CBDIS. Drs. Bergsma and Donovan are clinical professors of pediatrics at TUSM.

Operating through the telephone system, it will be possible to dial into the computer from anywhere in the United States and Europe. By next year, the National Foundation expects to have at least one computer terminal in each of the 50 states, to provide instant, 24-hour access to the Boston-based information system, according to Dr. Arthur Salisbury of the National Foundation.

A pediatrician or physician can dial the Birth Defects Information Service computer, put his telephone into a special cradle, and use a computer terminal to feed in information about the child’s physical abnormalities, symptoms and biochemical findings. The computer will search its memory for possible diagnoses, then in further interaction with the doctor will ask for enough detail to zero in on the probable diagnosis.

March of Dimes chapters throughout the nation will assist local medical centers and hospitals with funds for equipment or personnel to initiate access to the new system. The first grants will be made to major medical centers to which the most baffling birth defects cases are usually referred. Community hospitals and other institutions are expected to be gradually phased into the network.

Eventually, the CBDIS will also operate as a birth defects registry, classifying previously unknown birth defects and matching scattered reports to identify “new” syndromes. By alerting health professionals to an increase in certain birth defects, it will give valuable extra time to trace causes before many children are affected. Assuring patient privacy, however, a patient’s name will never be recorded. The infant and family names will remain known only to their family physician.

The system also has potential as an educational tool to train medical students in birth defects medical terminology, diagnostic procedures and other aspects of medical practice relating to birth defects.

Finally, the information system may be used to assist in research of causes of birth defects.

In the United States alone, more than a quarter of a million children are born with birth defects each year. In addition to the children’s lives, the emotional and financial lives of their immediate families are greatly affected. The system is directed toward helping children, their families, the community, and, ultimately, future parents and their relatives.

The CBDIS will be operated as a division of T-NEMC, in collaboration with the National Foundation-March of Dimes.