
Fact Sheet

The Genetic and Rare Diseases Information Center

A rare disease typically affects a patient population estimated at fewer than 200,000 in the U.S. There are more than 6,000 rare diseases known today and they affect an estimated 25 million persons in the U.S.

Yesterday

- In 1989, the National Commission on Orphan (Rare) Diseases found that patients and families as well as physicians had great difficulties obtaining needed information about rare diseases.
- The Commission recommended a central source of information on rare diseases to facilitate access to information for patients and their families and to draw from existing information systems in the public and private sectors.
- In 1999, the Special Emphasis Panel of the National Institutes of Health (NIH) on the Coordination of Rare Diseases Research reinforced the findings of the Commission.
- Though great strides had been made through the Internet and various data bases, more needed to be done to provide information to patients and their families through multiple channels.
- The Information Center provides comprehensive responses by telephone, e-mail, letter, and fax in English or in Spanish.
- The responses contain up-to-date, reliable, and useful summaries of information and contact information for the information sources.
- Feed-back from information seekers has been overwhelmingly positive.

Tomorrow

- To ensure easy access to comprehensive information on rare diseases, the Information Center continues to change to meet the future information needs of the public. It will expand open and instantaneous access to patients, families, and to the health professions.

Today

- The Rare Diseases Act of 2002 included directions for the Office of Rare Diseases to support a centralized clearinghouse for rare diseases information.
- The Office of Rare Diseases partnered with the National Human Genome Research Institute and established the Genetic and Rare Diseases Information Center. Now in its fifth year, the Information Center has provided approximately 15,000 responses about 4,000 different rare and genetic diseases. The responses draw from existing information systems in the public and private sectors.

Contact Information

By Telephone: (888) 205-2311 (Phone);
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Number)

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