



Stephen C. Groft, Pharm.D.

Stephen Groft is currently a Senior Advisor to the Director, National Center for Advancing Translational Sciences (NCATS) at National Institutes of Health (NIH). Previously, he assisted in establishing the Office of Orphan Products Development at Food and Drug Administration (FDA) in 1982. After serving as the Executive Director of the National Commission on Orphan Diseases from 1987 to 1989, he established a rare diseases initiative at NIH. He served as the Director of the Office of Rare Diseases Research (ORDR) in NCATS at the NIH from 1993 until his retirement in 2014. His major focus has been on stimulating research with rare diseases and orphan products and developing information for patients, families, health care providers, research investigators, the biopharmaceutical industry, and the public. The emphasis included information about rare diseases, active and completed clinical trials, ongoing research, and patient advocacy groups. The ORDR has co-sponsored over 1,300 rare diseases-related scientific conferences and workshops to assist in identifying research priorities and the development of research agendas for the investigation of rare diseases. Previous activities included the development of the Genetic and Rare Diseases Information Center (GARD), the International Rare Diseases Research Consortium (IRDIRC), the International Conference on Rare Diseases and Orphan Drugs (ICORD), the Rare Diseases Clinical Research Network (RDCRN), assisting in the development of the Undiagnosed Diseases Program at NIH's Clinical Research Center Hospital, and developing common data elements for patient registries. Current emphasis at NCATS is on patient engagement in research, medical devices in rare diseases, the international classification of rare diseases, and expanding the Undiagnosed Diseases Network into an international collaborative effort. He has authored 75 journal articles and book chapters and made over 300 presentations on rare diseases.

Stephen received the Bachelor of Science degree in Pharmacy in 1968 and the Doctor of Pharmacy degree from Duquesne University in 1979. Stephen retired in 2000 after a 30 year career as a commissioned officer in the United States Public Health Service.