

Stephen Groft

Steve is currently a Senior Advisor to the Director, National Center for Advancing Translational Sciences (NCATS) at NIH. Previously, he assisted in establishing the Office of Orphan Products Development at FDA in 1982, served as the Executive Director of the National Commission on Orphan Diseases from 1987-1989, and served as the Director of NIH's Office of Rare Diseases Research from 1993-2014 stimulating rare diseases research and developing information for patients, families, health care providers, academic/foundation research investigators, the biopharmaceutical industry, and the public about rare diseases, ongoing and completed research and clinical trials, and patient advocacy groups. Stimulated the development of the Genetic and Rare Diseases Information Center, the International Rare Diseases Research Consortium, the International Conference on Rare Diseases and Orphan Drugs, the Rare Diseases Clinical Research Network, assisting in the development of the Undiagnosed Diseases Program at NIH, and developed common data elements for patient registries. ORDR co-sponsored over 1,300 scientific conferences to assist in identifying research priorities and developing research agendas for the investigation of rare diseases.

Steve received the Bachelor of Science degree in Pharmacy in 1968 and the Doctor of Pharmacy degree from Duquesne University in 1979.