



## **Peter L. Saltonstall** **President and Chief Executive Officer**

Peter L. Saltonstall is the President and CEO of the National Organization for Rare Disorders (NORD®). He joined NORD in 2008 after having served for more than 30 years as a senior executive in both for profit and nonprofit healthcare environments.

Under his leadership, NORD has maintained the integrity of the Orphan Drug Act while forging new relationships between the patient community and the executive branch, Congress, US Department of Health and Human Services (HHS), Food and Drug Administration (FDA), National Institutes of Health (NIH), Social Security Administration, Centers for Medicare and Medicaid Services (CMS), drug and device companies, and with the medical, academic and investment communities. His efforts to collaborate and build partnerships stems from his view that advances for the rare disease patient can be achieved best through joint efforts. Today, Peter continues to be one of the countries lead voices on rare disease issues to industry, FDA, Congress and the government.

Peter is committed to globalization of the rare disease patient community, as diseases do not recognize geographical boundaries and research can be expedited when patients from many countries are involved. He has helped established collaborative programs with patient communities throughout Europe, Australia, Japan, Asia and South America.

Under Peter's leadership, NORD has grown to be the global reference site for the rare disease community, with NORD's website now receiving more than one million requests a month for information. He has also overseen the expansion of NORD's US based Patient Assistance network, which works with manufactures and patients to provide medication assistance to patients in need of medications they cannot afford. He also played a major role in the building the NORD longitudinal natural history system that is recognized by the FDA as one of the tools of choice for patient organizations collecting data on their disease.

Before joining NORD, Peter held senior positions with several major academic medical centers and organizations, including Harvard's Brigham and Women's Hospital, Tufts-New England Medical Center and St. Elizabeth's Medical Center of Boston. He helped launch Harvard Risk Management Foundation's startup venture, Risk Management Strategies, and the University of Pittsburgh Medical Center's private equity arm, Strategic Business Initiatives.

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In addition, Peter was the co-founder and CEO of SafeCare Systems, LLC, which developed one of the country's first patient safety management systems. He also played an active role on Capitol Hill in the development of the Patient Safety Act of 2005, which dramatically improved the reporting of events that adversely affect patients.

Peter currently serves on the NIH's NeuroNEXT External Oversight Board, the CTSA Consortium Coordinating Center External Advisory Board, International Rare Diseases Research Consortium Executive Committee and is a founding and current board member of the Medical Device Innovation Consortium (MDIC). Peter also serves on the Board of Directors and Executive Committee of MIT's NEW Drug Development ParadIGmS (NEWDIGS) program.

