



Edward Neilan
Chief Medical and Scientific Officer

Dr. Edward “Ed” Neilan is the Chief Medical and Scientific Officer of the National Organization for Rare Disorders (NORD). Ed is a physician-scientist and rare disease expert and he joined NORD in 2021 to lead its medical and research programs.

Ed seeks to encourage and enable institutions and companies to develop innovative approaches and new treatments to help rare disease patients. He is an expert in clinical trial design and drug development, has contributed data that helped support the FDA and global regulatory approvals of five new rare disease therapies, and has authored or co-authored multiple clinical trial protocols and safety and regulatory reports to global health authorities.

Prior to joining NORD, Ed worked at Sanofi Genzyme, a major biopharma company, where he led global medical affairs strategy and execution for the rare neurological diseases portfolio and contributed medical expertise to clinical development efforts across multiple programs. Prior to that, he served as the President of the Medical Staff at Boston Children’s Hospital. As a staff physician, clinical geneticist, and the Director of Quality Improvement in the metabolism program at Boston Children’s, Ed directly cared for and studied patients with many genetic diseases.

After completing BS and MS degrees in Biology at Yale University, Ed earned his M.D. and Ph.D degrees at Stanford University. He completed residency and fellowship training at Harvard Medical School, where he subsequently served as a faculty member for more than 12 years. Ed is triple board-certified in pediatrics, clinical genetics, and clinical biochemical genetics. He is a fellow of both the American Academy of Pediatrics and the American College of Medical Genetics and Genomics.

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