Professor Milan Macek Jr. MD, DSc is the chairman of the largest academic medical / molecular genetics institution (Department of Biology and Medical Genetics; DBMG) in the Czech Republic and cochair of the National Cystic Fibrosis Centre. He is also the past President of the European Society of Human Genetics (2011; www.eshg,org) and past-board member of the European Cystic Fibrosis Society (2007-2014; ECFS.eu). He was member of the EUCERD.eu committee, and currently serves as an EC-appointed expert at the Commission Expert Group on Rare Diseases. His department was designated by the Czech Ministry of Health as a National Coordination centre for rare diseases (www.nkcvo.cz) and serves as a "clearing centre" (Min Health Bulletin 4/2012) for dissemination of knowledge in rare disease-related genetics gathered within various international European projects related to rare diseases. His main research and clinical interes is molecular genetics/genomics in rare diseases, and how to bring genetics knowledge to the bedside. Prof. Macek is also the Czech National coordinator of Orphanet and member of the Diagnostic Committee of the International Rare Disease Consortium (www.irdirc.org).