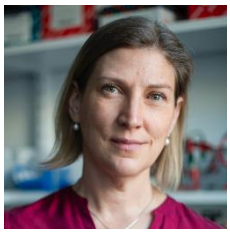
SPEAKERS

Nick Bishop

Nick Bishop is Professor of Paediatric Bone Disease at the University of Sheffield. He is co-chief investigator on the MOI – A study, looking at repurposing losartan in adults and older adolescents with osteogenesis imperfecta and global chief investigator for the Ultragenyx-sponsored studies of setrusumab in children and young adults with osteogenesis imperfecta. He is Associate Director of the Versus Arthritis Experimental Arthritis Treatment Centre for Children a Trustee of the Brittle Bone Society and an Honorary Fellow of the Royal College of Paediatrics and Child Health.

Cecilia Götherström



Cecilia Götherström is Associate Professor in Stem Cell Research at Karolinska Institutet in Sweden, and her research is on translational regenerative medicine. Dr Götherström has developed the Advanced Therapy Medicinal Product fetal mesenchymal stem cells as a treatment for Osteogenesis Imperfecta with promising results. Dr Götherström is leading a Horizon 2020-funded academic international multicentre project and clinical trial, Boost Brittle Bones Before Birth (BOOSTB4), which is the first of its kind to evaluate the safety and the clinical effect of mesenchymal stem cell transplantation for the treatment of severe Osteogenesis Imperfecta in infants and unborn children. The project also included summarising applicable laws and regulations, ethics related to the project and trial that includes vulnerable populations, investigating stakeholders' views, and evaluation of benefit-risk, Quality of Life and Health economics.

Marie Holm Laursen

Marie Holm Laursen is 27 years old and lives in Denmark. She has a degree in communication and works as a speaker with the vision of spreading joy and breaking down barriers for people living with a disability. Marie has OI type 3 and has had about 500 broken bones. She also participated in the ASTEROID Study.

Marina O'Callaghan

Marina O'Callaghan is currently our appointed REMEDi4ALL Patient Advocacy Group (PAG) Chair. She has OI Type 1A herself, as one of her two children has. Marina is a retired teacher (offender learning sector) and very keen to work with others to improve the quality of life for those with OI.

Patricia Osborne

Patricia Osborne CEO of Brittle Bone Society (BBS) UK Charity. Maintaining provision of the Charity's wheelchairs/equipment grant scheme and liaising with the Charity's Medical Advisory Board to develop useful factsheets and information. Working to provide relevant programmes of engagement and peer support with direct input from the wider community. Ensuring growth of our Research Grants programme alongside our Scientific Advisory Board and building relationships within the healthcare landscape.

Luigi Picaro

Luigi Picaro is currently Head European medical affairs at Mereo BioPharma. He is a fully qualified physician owning a post medical degree in Internal Medicine. Luigi has more than 30 years' experience in leading Pharma companies/biotech covering key roles in Clinical and Medical Affairs with a particular focus on Rare and Orphan Diseases.

Miguel Rodríguez Molina

Miguel Rodríguez Molina is a Physiotherapist from AHUCE and Fundacion AHUCE in Spain and actually enrolled in a PhD at the Universidad de Alcalá. He is a Clinician and researcher with a wide experience in treatment of bone dysplasias, especially osteogenesis imperfecta and is also Member of the Medical Advisory Board of the OIFE.

Inger-Margrethe Stavdal Paulsen

Inger-Margrethe Stavdal Paulsen has a degree in Education from Østfold University College in Norway and works part time as an elementary school teacher. She is chair of the Norwegian Osteogenesis Imperfecta Association (NFOI), a volunteer position she has had since 2016. Inger-Margrethe is the Norwegian delegate to OIFE, a delegate to the collaboration of rare disease organizations in the Nordic countries (SBONN), and a member of the EURORDIS HTA Task Force. She has a particular interest in patient involvement and is a graduate of the EURORDIS Open Academy School on Medicines Research and Development, has completed the EUCAPA Fast-Track Training and is currently enrolled in the EURORDIS Open Academy School on Scientific Innovation & Translational Research.

Violeta Stoyanova-Beninska

Dr. Violeta Stoyanova-Beninska is the Chair of the Committee for Orphan Medicinal Products (COMP) at the European Medicines Agency (EMA) since 2018. Before that she has been member of the COMP representing The Netherlands, Chair of the National Scientific and Regulatory Advice at the Medicines Evaluation Board, member of CNS working party and Scientific advice working party at EMA. Violeta is vice chair of the Regulatory Scientific Committee of the International Rare Disease Research Consortium. She is also member of scientific and advisory boards of international projects related to rare diseases, personalized medicine and orphan drug development. Besides her work as a regulator, Violeta is academic supervisor of PhD and master students, guest faculty at several universities, member of editorial board/reviewer panel in scientific peer reviewed journals.

Anna Rossi

Anna Rossi, OIFE Board Member, and Communication Manager, is an experienced advocate for disability rights and community empowerment with experiences not only in OI but also with other impairments and disabilities as she also collaborates with UILDM (Unione Italiana Lotta alla Distrofia Muscular) and with Ledha Milano (an organization about rights of people with disabilities in the Milan city area). Anna is a powerchair Hockey athlete and manager both nationally and internationally and para-sport enthusiast always advocating for sports inclusion for all.

Lidiia Zhytnik

Dr. Lidiia Zhytnik is a board member of the Care4BrittleBones Foundation. Dr.Zhytnik is a molecular geneticist with a broad interest towards bone fragility disorders. She is currently working as a Visiting Postdoc at the Amsterdam UMC, the Netherlands and a Researcher at the University of Tartu, Estonia. As a person with OI, she is particularly interested in OI preclinical and translational research and bridging collaboration between patients and professionals. Dr. Zhytnik is also involved in the OIFE activities as a Medical Advisory Board member.