



Brittle Bone Society SCIENTIFIC SYMPOSIUM

February 24th 2017 - Jones Day, London
Programme

09:15 *Registration*

09:45 Opening Address & Welcome

Jonathon Little, of Jones Day advises on the full span of IT matters, including e-commerce, network service arrangements and software procurement. Jonathon has been providing pro-bono advice to the Brittle Bone Society for a number of years. (*Deputising for BBS Vice Chairman John Phillips.*)

Professor Nick Shaw, is part of a multidisciplinary team that provides a comprehensive service for children and adolescents with Osteogenesis Imperfecta at Birmingham Children's Hospital. His team also provide a clinical service for children with other metabolic bone disorders.

10:00 Genetic Causes of Osteogenesis Imperfecta: 20 and Counting

Dr Fleur van Dijk, since 2006 many new genetic causes of OI have been discovered. Implications for the clinical and laboratory diagnosis of OI will be discussed.

10:45 *Coffee Break*

11:00 Orthopaedic Management of OI in Sweden

Dr Henrik Wehtje, modern orthopaedic fracture treatment and realignment of long-bone deformity in children and adolescents with Osteogenesis Imperfecta.

11:45 Quality of Life in OI

Dr Claire Hill, this presentation will review literature surrounding quality of life in Osteogenesis Imperfecta, attempting to answer the question, what is it we are measuring and why?

12:30 *Lunch*

13:30 What's new in OI therapeutics?

Professor Nick Bishop, we have used bisphosphonates for two decades in OI; as other antiresorptives, anabolics and matrix-directed treatments emerge, we must assess their utility and impact.

14:15 Advances in the Prenatal Management of OI

Professor Lyn Chitty, prenatal diagnosis and management of OI will be discussed, including advances in definitive molecular genetic diagnosis using rapid exome sequencing to allow in-utero therapy.

15:00 *Coffee Break*

15:15 Treatment for adults with OI

Dr Richard Keen, will discuss treatment for Adults with OI, the current landscape and change required now and in to the future.

16:00 Standards of Care for Children with OI

Professor Francis Glorieux, worldwide use of bisphosphonates makes it the current standard of care for OI even though it is officially approved in only two countries, Japan and Italy. As new therapeutic molecules are identified, parallel efficacy trials will be designed. In all cases, rehabilitation programs and timely corrective surgery have to be included.

Opening Address & Welcome



Prof. Nick Shaw
Consultant Paediatric
Endocrinologist - Birmingham
Children's Hospital &
Chairman Medical Advisory
Board - Brittle Bone Society



John Phillips
Partner in Charge London -
Jones Day & Vice-Chairman
Brittle Bone Society

Speakers



Prof. Francis Glorieux
Emeritus Director of Research -
Shriners Hospital for Children
Canada, Emeritus Professor of
Surgery, Paediatrics and Human
Genetics - McGill University &
Chair, Medical Advisory Council -
OIF (*Sponsored visit by OIF*)



Prof. Nick Bishop
Professor of Paediatric Bone
Disease - University of
Sheffield & Sheffield
Children's Hospital, Trustee
- Brittle Bone Society &
Chairman - Brittle Bone
Society Research Committee



Dr Fleur van Dijk
Consultant in Clinical Genetics -
North West Thames Regional
Genetics Service, London &
consultant in clinical genetics,
department of medical genetics,
University Medical Center
Groningen, the Netherlands



Prof. Lyn Chitty
Professor of Genetics and
Fetal Medicine - UCL GOS
Institute of Child Health and
Great Ormond Street NHS
Foundation Trust



Dr Henrik Wehtje, MD
Orthopaedic Consultant of the
OI-team at Astrid Lindgrens
Children's Hospital, Karolinska
Hospital, Stockholm, Sweden



Dr Claire Hill
Physiotherapist - Sheffield
Children's Hospital



Dr Richard Keen
Consultant Rheumatologist -
Royal National Orthopaedic
Hospital, Stanmore, London
& Chairman - Brittle Bone
Society Adult OI Forum

Chairman's Welcome

Welcome to our Charity's first event exclusively for Healthcare Professionals. We are delighted that Professor Nick Shaw and colleagues have been able to create a suitable platform where professionals can come together to share, debate and explore methods of treatment and exciting developments in the field of OI health.

Our strategic plan has listed greater uptake in Research to be a key milestone in our Charity's development and progress – and we are certain the BBS Symposium will be a regular event for the OI Calendar in the UK.

28 Feb 2017 will be the 10th International Rare Disease Day. It is heartening to know this year's international 'theme' is RESEARCH; and will coincide with the launch of our Scientific Symposium, our Research Grants programme and a year which will see our OI community grow their direct involvement in crucial studies and trials, while playing their part in finding new and better treatments.

Thank you for joining the Brittle Bone Society and associated Healthcare Professionals' to work together to gain a better understanding of OI.



Elaine Healey
Chairman Brittle Bone Society