

GLOBAL CME MASTER SERIES FOR FOP

OVERVIEW

The first Global CME Master Series for Fibrodysplasia Ossificans Progressiva (FOP) was developed in consultation with the ICC (International Clinical Council) on FOP in 2020. The objective was to increase awareness, promote early detection and treatment of one of the world's most ultra-rare conditions. Launched in August 2020 and featuring expert speakers from South Africa to Brazil, Argentina, the Netherlands and United States, the CME Master series gives voice to the patient experience while detailing the condition, from diagnosis to treatment, patient management and support, ethics, and specialist procedures, urging Health Care Professionals (HCPs) to join the movement, identify those still undiagnosed and to help end their isolation.

Each masterclass in the Global CME Master Series was pre-recorded, self-contained and followed by a real-time Q&A session with the presenter. All material was accredited by the local Health Authority, HPCSA (Health Professions Council of South Africa) to earn CPD (CME) points. As the HPCSA is recognized internationally, these points were transferable to the HCP's country of origin.

The Series is currently available to HCPs and allied healthcare professionals free of charge on the MyMembership platform. Given the presentations are pre-recorded and professionally packaged, they can be repurposed for additional platforms and audiences. The material is available for licensing.

1. The series commenced with an **Introduction to FOP** by Dr Christiaan Scott, Associate Professor and Head of Paediatric Rheumatology at Red Cross War Memorial Children's Hospital and the University of Cape Town. Dr Scott has a special interest in Fibrodysplasia Ossificans Progressiva and serves on the International Clinical Council on FOP, the International Presidents Council for FOP and the Tin Soldiers FOP Outreach Board of Directors.
2. The 2nd masterclass, **Clinical Presentations, Progression and Co-Morbidities** was presented by Dr Robert Pignolo, MD, PhD. Dr Pignolo is the Robert and Arlene Kogod Professor of Geriatric Medicine and Chair of Geriatric Medicine and Gerontology at the Mayo Clinic College of Medicine.

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He has worked on basic science, translational, and clinical aspects of bone diseases, including FOP and non-hereditary forms of heterotopic ossification (HO), for over 20 years. Dr Pignolo is actively involved in the FOP community worldwide and is currently president of the International Clinical Council on FOP.

3. Dr Mona Al Mukaddam M.D., M.S. presented the 3rd masterclass on **Treatment Considerations**. Dr Al Mukaddam is an Assistant Professor, Departments of Medicine and Orthopaedic Surgery, at Hospital of the University of Pennsylvania and Director of the Penn Bone Center for the Division of Endocrinology. She is a world-renowned expert in Fibrodysplasia Ossificans Progressiva (FOP) and the Principal Investigator on industry-sponsored clinical trials in FOP. Dr Al Mukaddam is the founding member of the International Clinical Council (ICC) on FOP established to consolidate a global voice and publish guidelines for the best practices for clinical care and research in FOP.
4. For the 4th masterclass, site investigator in interventional trials for an experimental compound to block heterotopic ossification in FOP, Dr Edward Hsiao MD. PhD., presented an update on **Clinical Trials in FOP**. Dr Edward Hsiao is an Associate Professor and the Fellowship Director for the Endocrinology and Metabolism Program at the University of California, San Francisco, USA. Dr Hsiao sees patients with metabolic and rare bone diseases in the UCSF Metabolic Bone Clinic and serves as a member of the International Clinical Council on FOP and the International FOP Association Medical Registry Advisory Board.
5. Johannesburg born, Dr Clive Friedman gave a 2-part masterclass, **Oral Health: Risk Management (part I) and Dentistry: Intervention and Treatment (part II)**. Dr Friedman trained and worked in South Africa, Israel, England, USA, and Canada presents on Risk Management, Intervention and Treatment. Dr Friedman is a member of the ICC (International Clinical Council for FOP) and has given many Oral Health presentations to FOP family gatherings.
6. In the penultimate masterclass, Dr Zvi Grunwald, MD, FASA, talks to **FOP Anaesthesia and Airway Issues**. Dr Grunwald is the James D. Wentzler Professor and Emeritus Chair of Anaesthesiology at the Sidney Kimmel Medical College, Thomas Jefferson University, Philadelphia, PA and for 20 years has led the anaesthesia and multidisciplinary teams of experts caring for patients with FOP scheduled for surgical and interventional procedure at Thomas Jefferson University Hospital in

Philadelphia. The Center serves FOP patients arriving from five continents and dispatches its team to assist patients globally. Dr Grunwald serves as a member of the International Clinical Council for FOP.

7. The series concludes with a **Caring is part of the Cure** masterclass. Hosted by Dr Fred Kaplan, this masterclass features FOP journeys from patients to families and clinicians around the world. Dr Fred Kaplan is the Isaac and Rose Nassau Professor of Orthopaedic Molecular Medicine and Chief of the Division of Orthopaedic Molecular Medicine at the University of Pennsylvania's Perelman School of Medicine. He co-directs the Center for Research in FOP and Related Disorders and is recognized as the world's leading expert on genetic disorders of heterotopic ossification.

The **Caring is part of the Cure** masterclass shared stories from:

Dr Genevieve Baujat (Paris' Centre of Reference for Skeletal Dysplasia, Imagine Institut, and Necker Hôpital)

Dr Carmen De Cunto (Professor and Chief, FOP Clinical Advisor - Argentina, Pediatric Rheumatology Section, Department of Pediatrics, Hospital Italiano de Buenos Aires)

Dr Patricia L.R. Delai (Consultant Doctor for the Brazilian FOP Association, Researcher at Hospital Israelita Albert Einstein, Teaching and Research Institute, São Paulo, Brazil)

Dr Marelise Eekhoff (Amsterdam University Medical Centers, VU University Medical Center (VUMC) Amsterdam, Amsterdam Bone Center, Department of Internal Medicine/Section Endocrinology)

Dr Elizabeth Ho (Specialist Paediatrician, Rahima Moosa Mother and Child Hospital, Johannesburg, South Africa)

Dr Kebashni Thandrayen (Adjunct Professor at the University of Witwatersrand, Paediatric Endocrinologist, Paediatrics & Child Health Unit, Chris Hani Baragwanath Hospital).

RESULTS

The Global CME Master Series was attended by 357 healthcare and allied professionals from 16 countries across the globe.

- 265 of these attendees were HCPs and 9 Health Science Students, new to the FOP world
- The African Clinicians Collective increased from 1 to 8 HCPs with patients being identified in Ethiopia, Morocco, Cape Verde and more recently, Nigeria.
- Most attendees were General Practitioners and from Paediatric disciplines i.e. Paediatricians and Paediatric Dentists, -Endocrinologists, -Gastroenterologists, -Neurologists, -Rheumatologists and -Orthopaedic Surgeons. The Series also enjoyed good representation from Anaesthetists, Dentists, Endocrinologists, Geneticists, Internists, Neurologists, Neurosurgeons, Orthopaedic Surgeons, , Physicians, Rheumatologists and Surgeons
- The average attendance rate for the Series was 78% with attendees rating each masterclass around 7/10
- 90% of attendees learnt something new during the masterclass and 76% would recommend the Series to a colleague.

Our results speak for themselves! Here are some comments from attendees:

Thank you for such a great lecture. It is so informative.

Dr Motlatjo Maag

Thank you Prof & thank you Tin Soldiers for an excellent series. Really informative.

Dr Prashini Govender

I am a specialist anaesthetist, so this presentation was very valuable for me. thank you.

Dr Magdalena Ciborowski

Thank you for a wonderful talk.

Dr Vijay Jaganath

Thank you for an excellent session!

Dr Liliana Iosub

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