



FOR IMMEDIATE RELEASE

JOIN US AT THE HUNTERIAN MUSEUM

'First Do No Harm': Expert Reflections on a Rare Bone Disease'

Join **Medics4RareDiseases** and **FOP Friends** for a unique reception, at the prestigious **Hunterian Museum**, at the **Royal College of Surgeons of England** on **13th February 2024**. Aimed at healthcare professionals, the event will uncover the incredible advancements in the understanding and treatment of **Fibrodysplasia Ossificans Progressiva** (FOP), a rare genetic connective tissue disorder.

Clinicians, patients and advocates will share stories about the lived experience of people with FOP from the 18th century to the present day. Attendees will also get the opportunity to see, in the Hunterian Museum and RCSEng Anatomy and Pathology Museum, skeletons of two people who lived with FOP, two centuries apart, one in the mid 1700s the other at the end of the 20th century. The event is from 5.30 - 9.00 pm, with drinks and canapés provided.

About FOP

FOP is an example of a rare genetic condition that has been familiar to medicine for hundreds of years, but is not familiar to the average healthcare professional. It is characterized by the abnormal development of bone in skeletal muscles and connective tissues, progressively locking joints in place and limiting movement. Affecting only one in a million, the acknowledged history of FOP is largely thanks to patients and families who have given their time, stories, samples and even their bodies, to improve the outlook of future patients.

Unique Insight

With case studies reaching back as far as the 18th Century, this event will provide a unique insight into how far knowledge and treatment for this rare condition have advanced. You will hear from clinicians and advocates who have been pivotal in advancing treatment and improving the lives of those living with this rare condition. You will also hear real-life stories from people living with FOP. Talks will exemplify the importance of patient advocacy in the advancement of rare genetic conditions. They

will also serve as a reminder about the principles of clinical care that can make all the difference to those living with rare diseases.

Speakers

- **Professor James Triffitt** - Professor Emeritus of Bone Metabolism, University of Oxford
- **Professor Richard Keen** - Consultant in Rheumatology and Metabolic Bone Disease, Royal National Orthopaedic Hospital
- **Chris and Oliver Bedford-Gay** - FOP Friends
- **Lucy Pratt** - Patient advocate
- **Dawn Kemp** - Director of Museums - Royal College of Surgeons of England

Register and reserve your place here:

<https://www.eventbrite.co.uk/e/first-do-no-harm-expert-reflections-on-a-rare-bone-disease-tickets-759562561067?aff=oddtcreator>

Or for further information, please contact: nadine@m4rd.org

About Medics4RareDiseases

Medics4RareDiseases (M4RD) is a registered charity committed to providing and promoting rare disease education for medical professionals, students, and doctors in training, with the primary goal of helping improve the journey through healthcare for people living with rare diseases, in order to achieve an earlier diagnosis.

m4rd.org

About FOP Friends

FOP Friends is the UK's only charity which is dedicated to supporting people living with FOP and their families. Their aim is to further research into Fibrodysplasia Ossificans Progressiva (FOP) and related conditions by supporting current and future research projects, and support those living with FOP and their families. <https://www.fopfriends.com>

About the Hunterian Museum

The Hunterian Museum, named after the 18th century surgeon and anatomist John Hunter (1728-1793), reopened in May 2023 following a five-year redevelopment of the Royal College of Surgeons of England's headquarters in central London. The £4.6 million museum development includes the display of over 2,000 anatomical preparations from Hunter's original collection, alongside instruments, equipment, models, paintings and archive material, which trace the history of surgery from ancient times to the latest robot-assisted operations. The Museum includes England's largest public display of human anatomy. <https://hunterianmuseum.org>