March 8, 2019

Dear Members of the FOP Community,

On behalf of The International Clinical Council on FOP (ICC), its 21 members and five consultants, we are pleased to introduce the 2019 edition of

THE MEDICAL MANAGEMENT OF
FIBRODYSPLASIA OSSIFICANS PROGRESSIVA:
CURRENT TREATMENT CONSIDERATIONS

(also known as, **The FOP Treatment Guidelines**).

The ICC has been working assiduously on this document for over a year which represents a monumental effort on the part of many. This report contains fifteen new sections that we hope you will find useful as well as completely updated sections that you found useful in the past.

You will notice the new **Executive Summary of Key Practice Points** (Section II). It is conservative, informative and balanced – and supported by the detailed exposition of the larger report.

We emphasize that this document reflects the authors' experience and opinions on the various topics and classes of symptom-modifying medications, and is meant only as a guide to this area of therapeutics for an ultra-rare condition for which evidence-based information is limited.

Although there are common physical features shared by every person who has FOP, there are physiological differences among individuals that may alter the potential benefits or risks of any medication or class of medications discussed here. The decision to use or withhold a particular medication must ultimately rest with an individual patient and his or her physician.

With ongoing clinical trials and additional ones on the horizon, we anticipate that this document will be updated annually – more frequently if needed.

We sincerely hope that this revised edition of the **FOP Treatment Guidelines** will be useful and relevant to FOP patients, families, physicians, dentists, medical personnel and caregivers worldwide.

Sincerely,

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Corresponding Editors