



Welcome to the first of our twice yearly updates for clinicians involved or interested in the management of **Fibrodysplasia Ossificans Progressiva**

**Issue 1 February 2017**

### Phase II palovarotene trial currently enrolling in Australia!

Clementia Pharmaceuticals have released topline results from the first, 12 week stage of their phase II trial of RARy specific agonist palovarotene in forty people with FOP. This demonstrates an acceptable adverse effect profile, will all adverse effects either treatable by over the counter products or not attributable to the drug. Efficacy data suggests a trend towards a reduction in new heterotopic ossification, but doesn't reach statistical significance.

The second stage of this trial, **An Open-Label Extension Study of Palovarotene to Treat Preosseous Flare-ups in FOP Subjects** is currently open for enrolments at the Queensland University of Technology. This stage will follow the 40 participants from the first stage, and enroll 20 new participants in this 24 month study. Trial details including inclusion criteria are available on **clinicaltrials.gov (study code NCT02279095)**.

Contact Linda Bradbury 07 3443 7077  
[linda.bradbury@qut.edu.au](mailto:linda.bradbury@qut.edu.au) for more information.

### Treatment Guidelines

Links to the International FOP Association (IFOPA) **emergency treatment guidelines** are available at the top of every page on our website.

This will also lead you to the full copy of **'The Medical Management of Fibrodysplasia Ossificans Progressiva: Current Treatment Guidelines'** available for download.

### Free Membership

To help increase awareness of FOP, FOP Australia gives all clinicians get free lifetime membership, waiving the annual \$10 fee.

Contact us at [info@fopaustalia.org](mailto:info@fopaustalia.org)

Please share this message with your colleagues



### Focus on: Dental care

Routine dental work can cause significant problems for people with FOP. Remember the main points below:

- Maintaining good dental health is a priority for your FOP patients. Ensure they are aware of this and have an informed dentist involved in any issues
- Dentists treating FOP are strongly encouraged to seek expert assistance from a clinician experienced in the condition before undertaking any procedures.
- Mandibular blocks can cause TMJ ankylosis and are strictly contraindicated in FOP. Infiltrative anaesthetic techniques can be very difficult in FOP and must be done with caution. (Luchetti et al., 1996; Nussbaum et al. 1996)
- Your FOP patient may require a general anaesthetic for safe dental care, but all must be carefully planned and requires an anaesthetist informed and experienced regarding FOP.

FOP Australia and our international contacts would like to assist you if you have difficulty locating an experienced dentist or anaesthetist for your patient. Email: [info@fopaustalia.org](mailto:info@fopaustalia.org)

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