

Dear IFOPA Community Members,

Clementia Pharmaceuticals Inc. announced plans to initiate a Phase 2 clinical trial of palovarotene, an experimental RAR-gamma agonist, in adults with FOP. You can read Clementia's press release, along with a Q&A about the trial, in the links below. You can find key trial details, including a summary of the trial design, eligibility criteria, and participating sites, at www.clinicaltrials.gov (in the Search Studies box, enter identifier **NCT02190747** or **palovarotene**) or at www.clementiapharma.com.

This announcement is a tremendous achievement, not only for Clementia but for the entire FOP community. Jeannie Peeper said in response, "We have anticipated this day since the FOP gene discovery in 2006 and we celebrate this monumental occasion, which will bring us one step closer to our dream of a treatment and a cure for FOP. If you dream it, envision it, all things are possible!"

This moment marks the *beginning* of an incredibly important time for our community: an era of clinical trials. It is an era in which the active voice and presence of the patient community is as important as ever. It is an era of substantial hurdles and continued uncertainty. The IFOPA will work with Clementia and any other interested biopharmaceutical companies to overcome those hurdles and realize our vision of a safe, transformative therapy for FOP. We are already working hard to support drug development by establishing a global FOP registry, engaging with researchers at universities and drug companies worldwide, and hosting an FOP Drug Development Forum, to be held in Boston in November 2014, during which researchers can interact with each other around the key questions of FOP drug development.

The decision to participate in any clinical trial and receive an experimental therapy is one of the biggest decisions an individual may face. If you may be interested and are eligible to participate in a clinical trial, we encourage you to discuss it with your doctor and your family. If we at the IFOPA can help you get answers to your questions about a clinical trial so that you

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can make an informed decision about whether to participate, please let us know. We are committed to sharing up-to-date information and facilitating dialogue with appropriate experts to enable you to make an informed choice. You can reach us by email at questions@ifopa.org or by phone +1 (407) 365-4194.

Sincerely,

A handwritten signature in cursive script that reads 'Marilyn Hair'.

Marilyn Hair
Chair, IFOPA Board of Directors



“We have anticipated this day since the FOP gene discovery in 2006 and we celebrate this monumental occasion, which will bring us one step closer to our dream of a treatment and a cure for FOP. If you dream it, envision it, all things are possible!”

Jeannie Peeper, IFOPA Founder and President

To learn more about

- [Drug Development](#)
- [Clementia’s Clinical Trial Announcement](#)
- [Clementia’s Clinical Trial FAQs](#)

click on this link <http://www.ifopa.org/drug-development.html>