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Letter from the CEO

Clarissa Desjardins, Founder & CEO

Message to the IFOPA community

Dear members of the FOP community,

I wrote to you in November that Clementia's goal was to develop a treatment for FOP, and I am thrilled to write today that palovarotene is being tested in a clinical trial for FOP. This would not be possible without the hard-won gains of the FOP community over the last several decades. Your strength, heart, courage, and resolve compelled researchers to test the retinoids in animal models and enabled Clementia to take palovarotene, one of the drugs tested, into this clinical trial, the first of what we hope will be many and a step toward the ultimate goal of delivering a treatment for patients with FOP.

This Phase 2 clinical trial is designed to show whether palovarotene will have an effect on new bone formation during and after a flare-up in patients with FOP. Patients will be followed closely through in depth imaging studies, biomarkers, and patient-reported measures, all of which will likely set standards for future clinical trials. So regardless of palovarotene's effect, this trial represents significant progress that will improve understanding about FOP in meaningful ways.

Clementia is fully cognizant that emotions surrounding this disease are very personal and may be stirred by palovarotene's entry into the clinic. Some may rejoice at the symbolism of progress while others may recall their history with the disease. Ian Cali said it well when he said, "I don't even allow myself to believe a treatment may soon be on the horizon since I do not want it to affect my current happiness and acceptance." Although we cannot truly put ourselves in your shoes, we try, and that motivates us to execute this trial with utmost professional rigor, so that the data can begin to answer the questions we all have.

We do not know what the results of this clinical trial will be, and it would be irresponsible for us to speculate. We operate under regulatory guidelines that are in place to ensure that manufacturers do not try to influence unduly members of the disease communities whom they serve and, importantly, do not misrepresent any information about their experimental drugs. More importantly though, we do not wish to speak casually of things that are so important to so many, including ourselves. We will share the results of our work as quickly as possible. We see this first clinical trial as the beginning of a journey with you, one that is assuredly leading us forward in the right direction.

Best regards,

A handwritten signature in blue ink, appearing to read "Clarissa Desjardins".

Clarissa Desjardins