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Letter from the CEO, August 26, 2015

Clarissa Desjardins, Founder & CEO

Message to the IFOPA community

Dear members of the FOP community,

In November 2013, I first introduced myself to you as the founder of a company whose goal was to develop a treatment for FOP. At that time, we had recently licensed the rights to palovarotene and were preparing to initiate clinical trials. As we move forward in these trials, we increasingly understand the gravity of FOP and what an approved treatment would mean for affected families.

The importance of potentially treating children before their mobility is significantly affected is something we all appreciate. That is why I am delighted to share that children age six and older may now participate in the Phase 2 study.

The inclusion of children between six and 14 years old will allow for the preliminary assessment of safety in this age group, bringing us to the last step needed to conclude the Phase 2 study. We anticipate that if enrollment continues as planned, we will complete the Phase 2 study by the end of 2015 and will formally announce when this occurs. Once complete, we pledge to efficiently analyze the data so that we may announce the findings in 2016 and finalize the design of the Phase 3 study. Our goal is that children even younger than six years old may be able to be enrolled in the Phase 3 study.

In addition to the milestone of children enrollment, our clinical program is proceeding well. Individuals who complete the Phase 2 study can enroll in the open-label extension study and receive palovarotene for any subsequent, eligible flare-ups. To date, all individuals who have completed the Phase 2 study have chosen to participate in the open-label extension study.

Clementia's Natural History Study has been progressing at an extraordinary pace with 33 subjects enrolled and several others scheduled to be enrolled. Because of this progress, we have decided to increase enrollment from 50 to up to 100 participants. Through our data sharing agreement with the IFOPA, this crucial disease progression information will deepen the entire community's understanding of FOP.

It has been an exciting year at Clementia and for the FOP community. More than ever, there is interest in developing a treatment for FOP. I cannot express enough our gratitude to all of the individuals who have volunteered to participate in our trials and to all of the loved ones who have supported them. We are amazed by your resolve, inspired by your courage and appreciative of your willingness to embrace us into your community. We are hopeful for a brighter future for all those affected by FOP and will continue to work hand-in-hand with you to move our clinical program forward.

Best regards,

Clarissa Desjardins