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Letter from the CEO

Clarissa Desjardins, Founder and CEO

A message to 25th anniversary IFOPA celebration participants

Congratulations on all of your hard work! Twenty-five years of working together to help fund research, educate, support families and ultimately treat FOP is truly something to celebrate.

I am the founder and CEO of Clementia. Our goal is to develop a treatment for FOP. We are planning and preparing for clinical trials where we will be testing Clm-001, a drug that was originally in development by a large pharmaceutical company in another disease.

I'd like to tell you a little about how Clementia came to be. Basically, it all started with Nature Medicine paper by Drs. Iwamoto and Pacifici. As many of you know, this paper showed that RAR γ agonists could prevent heterotopic bone formation in animal models of FOP. I reached to the company whose drug was tested in this paper, and through several key contacts, found out that they were prepared to out-license the drug if sufficient funds could be raised to develop it. Fortunately, raising money for biotechnology companies is something I had done before.

One of the first calls I made before Clementia was even born, was to the person who had by far published the most on FOP, Dr. Frederick Kaplan. I knew after speaking with him and hearing his heroic story that this would be a very special journey. Through Dr. Kaplan, I was introduced to the Cali family. I'll never forget my first conversation with John Cali (whose son, Ian has FOP) where, in hearing that I was about to start a company and raise money for a clinical trial, he told me that he wanted to help me in any way he could. He said "there is nothing that I would not do or give to help develop a treatment for my son, Ian, and for all those with FOP". I'm sure he spoke for all of you when he said this. He then sent me a video of a speech by Ian, then 17, speaking about what it was like to live with FOP and what the prospects of new treatments meant to him.

Ian has become our inspiration. Everyone in our company has seen Ian's speech, including our Board. Ian was the first to inspire us but as we get to know more of you from the FOP community, Nathalie, Mathew, Sienna and all of you here, we continue to be inspired and we're rooting for you all.

I wish I could tell you that our drug or others in the pipeline will be successful in reducing bone formation, but no one knows this for sure. Only clinical trials can provide that answer. But I can tell you for certain, is that we are doing absolutely everything we can to initiate a safe and well-designed clinical trial which will answer this question.

Dr. Donna Grogan, our Chief Medical Officer and other members of our team are eagerly looking forward to working with you, the IFOPA, clinical experts and regulators to get these trials underway.

Best regards,

A handwritten signature in black ink, appearing to be "C Desjardins", written over a horizontal line.

Clarissa Desjardins