



**PXE International**  
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**eNewsletter**  
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## **COVID-19 Vaccines Informational Webinar**

We've received many questions about PXE and the COVID-19 vaccines and are happy to announce that there is a webinar this Saturday, February 20th, to address some of your questions.

In this webinar, Francis Collins, Director of the National Institutes of Health, will share with us why it is critical that individuals living with chronic diseases and conditions receive the coronavirus vaccine. He will describe the scientific evidence for the safety and efficacy of the vaccine and why it is important to get vaccinated when it is your turn. Dr. Collins has been a leader in the quest to develop the vaccines, and is working hard to make sure they are widely available. This meeting is hosted by Genetic Alliance.

This is not a PXE-specific webinar, but the question of rare diseases will be addressed. Register in advance for this meeting by clicking the button below. After registering, you will receive a confirmation email containing information about joining the meeting.

[\*\*Register to Join\*\*](#)

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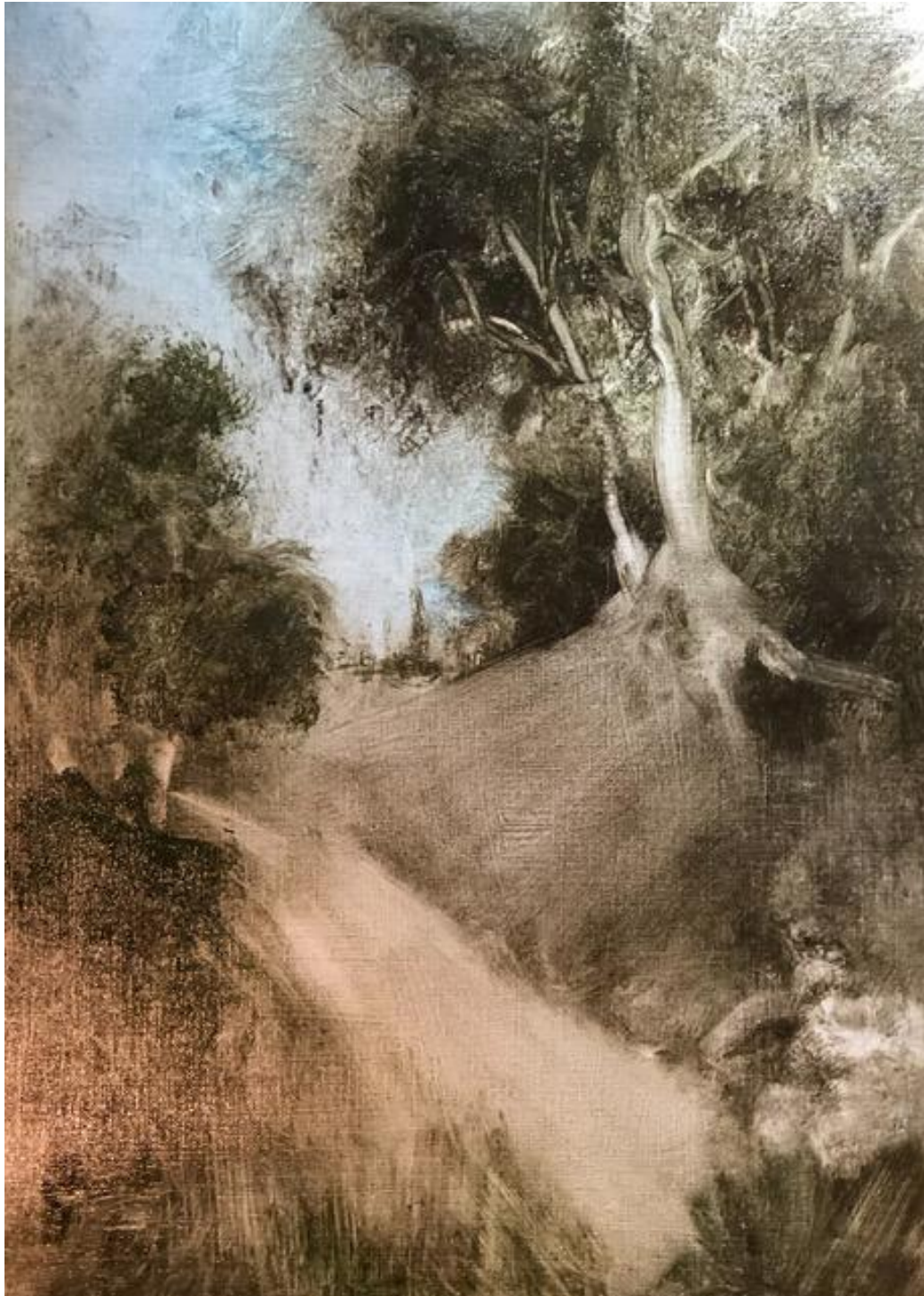
## **Painting with Colette**

Colette Wise is a PXEer and an artist. She first started having symptoms of PXE 5 years ago and now has vision loss in both eyes. When she was no longer able to work, she handed off her role as CEO of a non-profit, something she struggled to let go of, and turned to painting. Colette has always been an artist and started taking classes again a few years ago. With the vision loss, what used to take her hours now takes days and simple tasks like mixing paint are more challenging, yet this outlet is essential to her. She loves painting.

The art below was created over the past few years since Colette lost some vision. She says that she is still finding her voice and style and that she is nervous each time she paints. She believes that "being an artist is not about being perfect, it is

about expressing how you feel and working to get that feeling across.”

Colette is offering to connect with other PXEers for painting class via zoom. If you are interested in joining, email [Tamara Wurst](mailto:Tamara.Wurst) for more information.



Painting above: This is the technique that Colette would like to share with others losing their vision. It uses only 3 colors and was painted with Q-tips, paper towel, and a chip brush. Colette believes that people who think they can no longer be creative can do this technique.



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## Meet a PXE Researcher

Olivier Vanakker MD, PhD is a pediatrician and clinical geneticist affiliated with the Center for Medical Genetics of the Ghent University Hospital, Belgium. He is the principal investigator of the Ghent Ectopic Mineralization Research Group. The principal focus of the group is to understand how the genes of individuals with PXE might relate to the progression of the disease, if there is a relationship between specific genes and symptoms, and how this genetic information can be translated to the management and treatment of patients. Olivier has worked closely with PXE International to add to our understanding of PXE for almost 18 years and in his free time, he enjoys a good book and is a dedicated admirer of Salvador Dalí.



If you are interested in learning more about Olivier's work on PXE and related conditions, you can check out some recent webinars available on the PXE International YouTube Channel:

[PXE International Virtual Conference 2020: Genetics of PXE](#)  
[Zebrafish models for PXE. A Plunge into the water](#)  
[Genetics behind Pseudoxanthoma Elasticum](#)

You can also follow the Ghent Ectopic Mineralization Research Group on their new Instagram profile: [@EctopicMineralizationResearch](#)

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## Mindfulness Through Gestalt Awareness Practice

In response to the stress many PXEers reported feeling because of the pandemic, Sharon offered three online experiences of [Gestalt Awareness Practice](#), something she has studied for about five years. In these short practice experiences, Sharon helps open a space for you to feel support moment to moment. She offers tools to help ground you, even in a time of challenge. This practice can lead to self-support and openness to what is. Recordings of these guided practices for PXEers and others are [available here](#).

In addition, Sharon is offering a weekend retreat called Introduction to Gestalt Awareness Practice. She is offering a 10% discount to any PXEer or their supporting friends and family. For more information click [here](#).

[Listen to the Guided Meditations](#)

[PXE International](#)

