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**Tribute to Ivonne Pasquali Ronchetti**  
Rest in Peace • April 12, 2020 • Easter Sunday



Ivonne. I can still hear "ooo la la" - an oft uttered exclamation from my dear friend. I pause in that memory, hardly believing she is not with us any more. I am grateful I can hear that excited little trill.

Ivonne was a force of nature. She was one of the first researchers I met when it became apparent that we would have to move mountains to really rev up research on PXE. Ivonne Pasquali Ronchetti. How incredible it was that she took us into her work, her lab, and her home on our first visit to Italy in 1996. My children were 10 and 8 years old. We rented a motorhome and pulled into Modena Italy, home of balsamic vinegar.

PXE Italia folks met us, and took Elizabeth and Ian off to see the sites. I went to Ivonne's lab, not impressed by the brick and mortar, but by the shelves of notebooks that screamed "PXE" on their binder ends. Oh, my heart quickened, shelves of notebooks with the three letters that changed our lives forever. Someone who might meet my passion.

Ivonne took us seriously from the start. She drew diagrams and showed us her results before publishing them. We were taken by her intelligence, her warmth, and her sparkle. It was easy to see she would earn PXE International's financial

support for her work, and that of her young protege, Daniela Quaglino.

When our scientists fought, hoarded data, and ideas, I found refuge in Ivonne. We became good friends over these almost 25 years. I lamented with her in the loss of her dear husband Guelfo. I supported her when she struck out beyond the usual bounds of academia and founded the PXE Italia Association with many wonderful PXEers in Italy. We met together not long ago in Modena.

I am grateful that Ivonne and I had many emails back and forth in March as she lay dying. I am so happy that our last messages to each other included photos of the next generation in our families and always "Kisses and un grande abbraccio".

Ivonne, I will miss your kisses and hugs. I will miss your support. I will hear "ooo la la" and feel your warmth as a woman, and your wit as a scientist. You often said, "It is not normale". This is not normale.

We will celebrate the life and love of Ivonne Pasquali Ronchetti in an online memorial on Sunday, May 17th at 2 PM ET/8 PM CET. If you can join us, please do. Simply [register here](#) and you will receive instructions for connecting via video, audio, or both. We will join in a big Zoom meeting. We welcome memories and stories in both English and Italian. Daniela will attend and say a few words. We look forward to honoring Ivonne this way. Even if you did not know her, know that she paved the way for many of the discoveries we are building on today. Come celebrate her with us. We need you in our sorrow and loss.

In life,  
Sharon

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## 2020 Member Conference Postponed

After very serious deliberation, the board of PXE International has decided to postpone the 25th Anniversary celebration of our founding. Due to the developing projections on COVID-19 and predictions for an upswing in cases in the fall, we do not think our October dates are viable. As a foundation dedicated to health, we must lead the way and safeguard as much as we can. We will be rescheduling the meeting for sometime in 2021. Meanwhile we ask that you each be conservative in your management of your experience of COVID-19.

Please continue to follow CDC and WHO guidelines for staying safe and limiting spread of the virus. An easy way to do that is to visit the website we have collaborated on [Fight To End Covid](#),

Sharon and Ian have written blogs about COVID-19. You can access them here: <http://fight-cov19.com/>

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## Staff Updates

Please join us in welcoming Matthew Caffet to our PXE Team! He's currently working part time for PXE International, coordinating our research efforts on his

weekends.

Matthew was born in Canada, and grew up in Venezuela, a country he calls home. He has lived in the US for a while and has a BA from Stanford in medicinal chemistry. He is very well suited for these next years of therapeutic intervention in PXE.



Matthew joined Genetic Alliance as an intern in February and was quickly promoted to a full time staff position, while also assisting with PXE work. He enjoys working in the genetic and health advocacy spaces and is looking forward to developing more experience and knowledge in the future! He is an avid cook - ask him for a favorite Latin American dish and he will not disappoint! We are so grateful to have him with us! You can reach Matthew at [mcaffet@pxe.org](mailto:mcaffet@pxe.org).

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## New Webinar Available

Our latest PXE webinar is up now on YouTube! Stephanie Moore, PhD, of Vanderbilt University, presented recently on the ways that biomineralization affects PXE. Watch this webinar below and check out all of our previous webinars on the PXE International [YouTube channel](#).

## Have an idea for a webinar you'd like to see? Let us know!

If you have an idea for a webinar you'd like to present yourself, or a topic you'd like to see discussed, please email [Sharon](#).



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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 a little over four 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](#).

[Listen Here!](#)

[PXE International](#)

