ICIS Newsletter December 2023

Dear colleagues and friends

Please find below our December 2023 Newsletter.

PARC-ITP Registry

Our international PARC-ITP Registry is open since 2004. Since then, many national registries have been opened and it becomes increasingly difficult to maintain representative data reflecting country specific and more general aspects of ITP in such an international registry. Additionally, there is a growing need for more national legal requirements, which make an international project even more complicated. In order to maintain data quality and analytical projects concerning our Registry data, we therefore decided to close the Registry on December 15 of this year.

We appreciate your continued support and your active participation in this project. We think that we learned a lot of the natural history of ITP, of its pathophysiology and various clinical aspects of ITP. The Registry represented an important drive to promote knowledge in ITP by planning scientific projects and communication. The Registry data are still a rich source of analyses and scientific projects. ICIS is planning to continue its scientific activities. The PARC ITP Registry was a beautiful example of an international academic collaboration that functioned well thanks to your support and collaboration and with minimal costs.

Finally, a cordial thanks to Caroline for her precious and continuous work in this project. She will leave ICIS at the end of this year, and we wish her all the best for her professional and private future.

International ICIS Expert Meeting Lenzerheide 2022

Please be advised that the manuscripts based on the ICIS Expert Meeting 2022 in Lenzerheide, Switzerland on Refractory ITP: Characterization, Definition and Management, were recently published by the British Journal of Haematology: <u>BJH Wiley Online Library</u>. Together with these articles two videos with interviews with Jim Bussel and with Paul Imbach have been published by the British Journal of Haematology, please see

[https://players.brightcove.net/656326989001/default_default/index.html?videoId=6339543363112] and

[https://players.brightcove.net/656326989001/default_default/index.html?videoId=6339543964112]

As always, we are happy to receive your thoughts and suggestions. Again, a warm thank you for all your help and support.

Best regards

Paul Imbach Thomas Kühne Alexandra Schifferli Verena Stahel Chairman Chairwoman Coordinator