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LATEST NEWS AND ACTIVITIES



Members' Conference 2022

On Saturday 29 October and Sunday 30 October 2022 we will organize our annual worldwide members' conference in the Netherlands. This year the conference will be 'hybrid'. This means that members can choose to participate online/virtual or in-person at our location in the Netherlands.

Information and registration



Patient Advocate training

On Thursday 27 October and Friday 28 October, our patient advocates can attend training prior to the members' conference. See below for further details.

[More information](#)



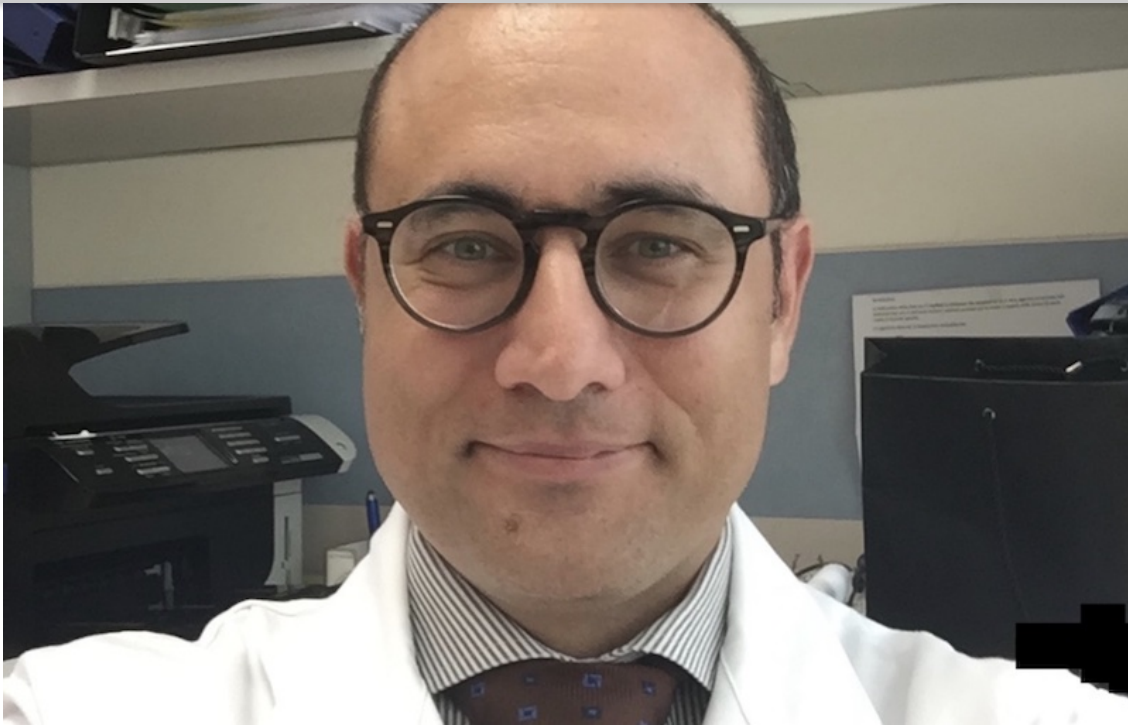
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Isolated and Classic CMTC

If you are looking for a good and comprehensive review article on CMTC, the article by Tamburro et al. 'Isolated and Classic Cutis Marmorata Telangiectatica Congenita' (9 June 2022) is highly recommended. Clinical and molecular diagnosis is discussed, which treatment should be used, how common is it, what needs to be checked regularly and is it genetically transmitted or not?

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Clinical features of vascular malformations and associated gene mutations

In the study described in the article by Diociaiuti (et al.) (photo above), researchers looked at the clinical features of a number of vascular malformations (VMs) and the corresponding genetic mutations in the DNA of the affected tissue.

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Parents Support Guide

We have developed a Parent Support Guide to help parents in their care for a child with a rare condition. The guide is available in several languages and for three age groups. The

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Family Day at the Efteling

On 2 July 2022, our Family Day took place at the Efteling. This year, we were finally able to organise this day in full again with 80 participants from Belgium, Germany and the Netherlands. Read and watch the report.

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