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LATEST NEWS AND ACTIVITIES



Member conference 2022

On Saturday 29 October and Sunday 30 October 2022 we will organize our annual worldwide member's 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

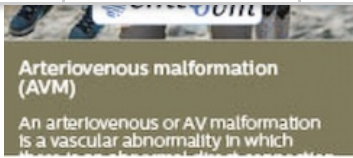

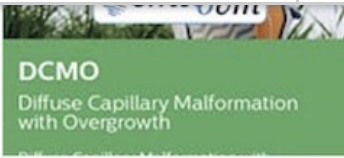





Launch Global Dermatology Coalition

On 25 May 2022 a patient-led multi-stakeholder group of like-minded organizations – including dermatology patient organizations, health care professionals (dermatologists and dermatology nurses), researchers, and industry – announced the formation of the Global Dermatology Coalition. CMTC-OVM is also part of this coalition.

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|  <p>Arteriovenous malformation (AVM) An arteriovenous or AV malformation is a vascular abnormality in which</p> <p>01. AVM FOLDER 01-04-2022</p> <p>▶ Read More</p> |  <p>CMTC Cutis marmorata telangiectatica congenita</p> <p>02. CMTC FOLDER 10-01-2021</p> <p>▶ Read More</p> |  <p>DCMO Diffuse Capillary Malformation with Overgrowth</p> <p>03. DCMO FOLDER 29-04-2022</p> <p>▶ Read More</p> |
|  <p>Klippel-Trenaunay Syndrome (KTS) Klippel-Trenaunay Syndrome (KTS) has three main features: a large port-</p> <p>04. KTS FOLDER 01-04-2022</p> |  <p>When your brother or sister is ill A sick child impacts the whole family, which sometimes leads to the siblings being overlooked.</p> <p>05. SIBLINGS FOLDER 10-01-2021</p> |  <p>The psychological aspects of living with a rare disease This is an information leaflet looking at possible</p> <p>06. PSYCHOLOGY FOLDER 10-01-2021</p> |

Information folders

We have a whole series of information folders available in multiple languages. All folders can be downloaded and it is also possible to have printed folders sent.

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Approval alpelisib by FDA

Novartis' medicine Vijoice® (alpelisib) has recently (6 April) been approved by the US Food and Drug Administration (FDA) for the treatment of patients with severe manifestations of PIK3CA-related overgrowth syndrome (PROS). Until today, the only treatment options for these patients are surgical or interventional radiology procedures.

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