

Cutis Marmorata Telangiectatica Congenita

& Other Vascular Malformations



Patient Advocate Profile

CMTC-OVM is a patient organisation operating worldwide in which the patient and their direct environment are placed centrally. The board members and all the volunteers from a variety of countries carry out their highly appreciated work with much drive and a great deal of enjoyment. Together we have already achieved a lot and we can continue to do so. We represent the interests of the patients, who are often children and their direct family and we help them in all sorts of practical ways. Thanks to our organisation, to be able to provide clarity to a patient in terms of his or her condition is something that gives us a wonderful feeling each time. Our international volunteers are pleased to be actively involved in an enthusiastic and professional team.

Subject	Description
Main tasks A patient advocate works in principle in the country where he/she is living.	 Initiate and maintain contacts with patients, family of patients and caregivers in order to improve the quality of life of people living with CMTC or other vascular malformations. This not only concerns the medical part but also the psychological and psychosocial parts. Increase the visibility of our organisation. Spread/share our social media messages and our information material such as brochures. Recruit members, donors and sponsors. Act as 'linking pin' between the specific country and the Dutch Board. Participate in conferences. Organise actions and events. Supply information in order to compose together with the Dutch Board the action plan.
Authorisations	 Purchase of supplies up to a preset amount (see the procedure handbook). Decisions to be taken in cooperation with other board members (as necessary when a certain financial limit is exceeded, see the procedure handbook).
Responsibilities	 Build networks in a particular country for patients, caregivers, etc. Recruit members, donors and sponsors. Represent of our organisation in a presentable manner.
Time required	The amount of time and how much time is time to be spend is determined by the person him/her-self.
Characteristics	 Analytical. Organised. Accurate. Empathetic. Patient. Determined. Inspiring. Bold. Proactive. Eager to learn. Motivated. Result focussed. Relationship builder and networker.
Knowledge and Skills	 Leadership knowledge and experience. MS-Office: Word, Excel and Powerpoint. E-mail software such as MS-Outlook and webmail. Social media skills such as Facebook and Instagram. Excellent skills native language spoken and written.



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	 English language spoken and written very well. Organisation and improvisation. Able to make and maintain contacts at nearly all levels (incl. professors and doctors). Highly preferable is knowledge and experience of the not-for-profit sector.
Min. Education Level	Bachelor's degree level.
Equipment	 Computer with loudspeakers, webcam and microphone. MS-Office. Internet access and e-mail. Telephone.
Compensation	 Hotel costs during visit to the Netherlands will be reimbursed for one night. Other expenses after approval by the Dutch Board. We will reward a Patient Advocates (PA) via an encouragement program when he/she introduces new members or donors by means of an expense allowance.