

## Cutis Marmorata Telangiectatica Congenita & Other Vascular Malformations





## **President 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	<ol> <li>Prepare the policy document.</li> <li>Prepare the annual report document.</li> <li>Prepare subsidy requests.</li> <li>Prepare and maintain the procedure handbook.</li> <li>Prepare and maintain the volunteers handbook.</li> <li>Prepare social media policy.</li> <li>Organise and lead the Annual Member Conference in The Netherlands.</li> <li>Organise the Family Day in The Netherlands.</li> <li>Maintain contacts with external suppliers.</li> <li>Maintain contacts with sponsors.</li> <li>Maintain contacts with external organisations (Eurordis, VSOP, NORD, etc.).</li> <li>Prepare and maintain contracts.</li> <li>Maintain contacts with medical advisors.</li> <li>Chair board meetings in The Netherlands.</li> <li>Manage volunteers (and other board members).</li> <li>Maintain the web site.</li> <li>Manage administration for the organisation.</li> <li>Project management of CMTC-OVM projects.</li> <li>Prepare project requests.</li> <li>Represent the organisation during (international) conferences.</li> <li>General Data Protection Regulation (GDPR).</li> </ol>
Authorisations	<ol> <li>Purchase of supplies up to a set amount (see the procedure handbook).</li> <li>Decisions to be taken in cooperation with other board members (as necessary when a certain financial limit is exceeded, see the procedure handbook).</li> </ol>
Responsibilities	<ol> <li>Enhancing the external image of the organisation.</li> <li>Steering the organisation forward on an ongoing basis.</li> <li>Organisational development.</li> <li>Inspiring the surrounding environment.</li> <li>Achieve results, when needed in cooperation with others.</li> <li>Representation of our organisation in a presentable manner.</li> </ol>
Time required	Twenty hours per week on average. Read and respond to e-mail on a daily basis.  Attending (international) conferences and conventions normally needs several days, for which travel to the USA for example could be required. Total time required on an annual basis is around 1000 hours.
Characteristics	<ol> <li>Analytical.</li> <li>Organised.</li> <li>Accurate.</li> </ol>



## **Cutis Marmorata Telangiectatica Congenita Other Vascular Malformations**





Knowledge and Skills	<ol> <li>Empathetic.</li> <li>Patient.</li> <li>Determined.</li> <li>Inspiring.</li> <li>Bold.</li> <li>Proactive.</li> <li>Commercially minded.</li> <li>Motivated.</li> <li>Result focussed.</li> <li>Relationship builder and networker.</li> <li>Leadership knowledge and experience.</li> <li>Project based work.</li> <li>MS-Office: Word, Excel and Powerpoint.</li> <li>E-mail software such as MS-Outlook and webmail.</li> <li>Dutch language spoken and written, as a first language.</li> <li>English language spoken and written.</li> <li>Possibly also a third language, German for example.</li> <li>Organisation and improvisation.</li> <li>WordPress for content management of our website. If not available then the association can arrange appropriate training.</li> <li>Able to make and maintain contacts at high management and political level.</li> <li>ICT is an important tool within our organisation and it is essential that the person who fills this role has wider knowledge and skills of ICT than only the specific items mentioned above.</li> <li>Currently working for or has worked for a minimum of (5) years in a commercial business.</li> <li>Highly preferable is knowledge and experience of the not-for-profit sector.</li> </ol>
Min. Education Level	Bachelor's degree.
Equipment	<ol> <li>A laptop computer from the association will be made available.</li> <li>MS-Office will be installed on the laptop computer from the association.</li> <li>A printer-scanner from the association will be made available.</li> <li>Internet access and e-mail.</li> <li>Telephone.</li> </ol>
Compensation	<ol> <li>Monthly domestic expense reimbursement (telephone, power and Internet).</li> <li>Daily allowance when travelling for the association.</li> <li>Expense reimbursement when travelling for the association.</li> </ol>