
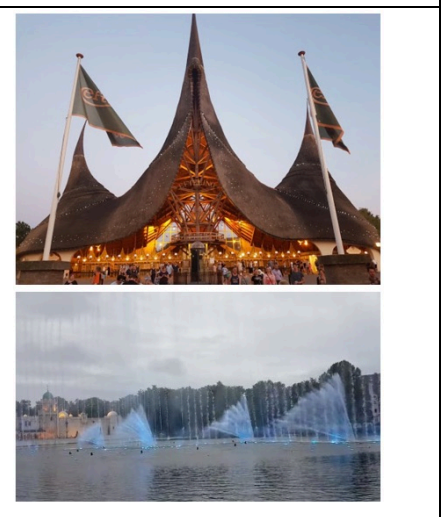
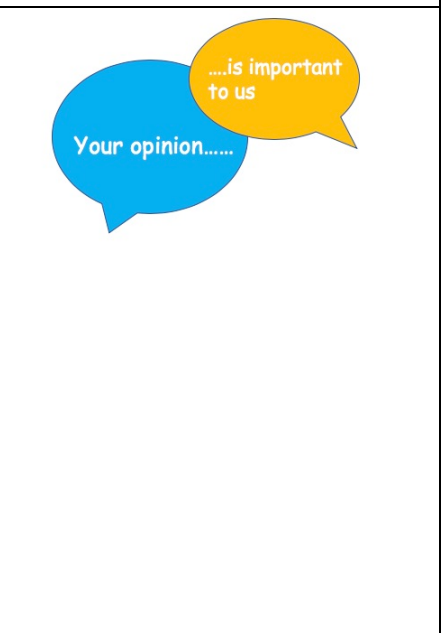



September 2019

	<p>Annual meeting of members</p> <p>On Saturday, November 2, 2019, we will again organize our global member conference. On Friday evening, November 1, we will receive our guests with a welcome drink and snack. In addition to various interesting lectures on Saturday 2 November, we offer the possibility for personal medical advice. For more information on the program and registration go to the CMTC website</p>
	<p>Family Day 2019 in Amusement Park Efteling</p> <p>On Saturday July 6, 2019 our international family day in the Netherlands took place in the Efteling. The day is the perfect opportunity to meet other members in an informal and very pleasant setting. You meet at the opening and lunch and the rest of the day you do the rides that you like. It was beautiful weather and everyone could go through the park until 11 pm! In total there were more than 80 people from different countries: the Netherlands, Belgium, Germany, England and Austria.</p>
	<p>Results of our global member survey</p> <p>In August 2019 we conducted a survey among our members to find out what their wishes are. The questions were mainly answered (88%) by parents of patients.</p> <p>Actions to be taken (based on all answers and comments):</p> <ol style="list-style-type: none"> 1. Organize more for patients and families to meet each other (virtual and / or personal). 2. Make the role of Patient Advocate clearer. 3. Train Patient Advocates. 4. Recruit more Patient Advocates. 5. Place more articles on our website about possible treatments. 6. Continue personal medical advice initiative and investigate online solutions. 7. Post more personal stories on the website and encourage people to share their personal stories. 8. Share website content regularly, eg once a week, via social

	<p>media such as psychological aspects of living with a rare disease.</p> <p>9. Offer members who are unable to physically participate in our global conference the opportunity to participate virtually via internet technology.</p> <p>10. More attention to communication about other vascular malformations in addition to CMTC.</p>
	<p>Wanted: youth board member</p> <p>We are looking for someone on our board to represent the young people</p> <p>Qualities required:</p> <p>You know what is going on among the young people (approx. 10 - 20 years) and know what they would like. You are creative, come up with proposals for activities and help to organise them. You are between 18 and 30 years old, can express yourself well in both Dutch and English, are independent and are yourself a patient or family member of a patient.</p> <p>Benefits:</p> <p>Would you like to gain knowledge and experience in an international organisation? Do you want to be active in social media? Do you want to expand your curriculum vitae in a unique way? And also receive an expense allowance?</p> <p>Interested?</p> <p>Are you interested? Send an email to secretariat@cmtc.nl with your background (can be a curriculum vitae), goals and motivation.</p>

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