Patient Journey Cutis Marmorata Teleangiectatica Congenita (CMTC)

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About CMTC
Cutis – skin
Marmorata – marbled
Teleangiectatica – abnormal bloodvessels
Congenita: present at birth
Occurrence: unknown
CMTC is both a skin disease as well as a vascular malformation

Introduction
The global CMTC-OVM was established in 1997 in the Netherlands to support patients and families, bring people together for peer contacts, information provisioning and patient advocacy. CMTC-OVM arranges consultation between patients, clinicians, psychologists, and other stakeholders. CMTC-OVM aims to stimulate a global collaboration in research and map the medical expertise in collaboration with the ERN-SKIN & ERN-VASCERN. These ERNs are the virtual expert centers networks with the aim to improve quality, safety and access to highly specialized healthcare for children and adults with rare skin and vascular diseases throughout Europe.

Methodology
A workshop was organized during the CMTC-OVM global conference in 2019. During the event an ERN-SKIN ePAG advocate collected feedback from the CMTC patient community and their families to draft their patient journey. These outputs together with CMTC experience for over 20 years were useful to map the needs and recommendations on ideal care across the different stages of the patient journey from the first symptoms at birth to the end-of-life care.

The document was also shared via the CMTC social media channels to collect feedback from the wider patient community (about 10 people reacted globally).

Overall patients and families needs across the 6 stages
✓ Immediate access to diagnosis by a multidisciplinary team in the right medical expertise center.
✓ Psychological and psychosocial support.
✓ Peer support from patient organisations.
✓ Access to reliable and understandable information on the disease and treatment plan.
✓ Understand the treatment options (do’ and don’ts) and the social impact on patients’ future life.
✓ Information about the risks, the expected results and each step of the treatment.
✓ Financial support if the costs for treatment and surgery are not reimbursed.
✓ Smooth transition from care to home.
✓ Best holistic care approach.

Overall patients and families ideal care and recommendations across the 6 stages
✓ Timely diagnosis in a reference medical center.
✓ Access to information material on disease and treatment plan.
✓ Access to quick psychological and psychosocial support.
✓ Direct contact with patient organisations.
✓ Social inclusion programmes offered by the schools to inform and facilitate the integration of the children.
✓ Smooth transition from child care to adult care.
✓ Medical data record in one single platform and accessible for the patients and families.
✓ Access to other treatments (camouflage technique instead of laser)
✓ Access to the best medical and palliative care services.
✓ Medical and genetic data available for further research.
✓ Creation of a social media memorandum page.

Conclusion
The patient journey is a tool that enables patient advocates to share and gather the needs from the perspective of the wider patient community. This is a reference document to develop a common understanding of the disease and the burden of the disease on both the patient and family. It is a good instrument to engage with the clinicians and to address these unmet needs.

The CMTC patient community involved emphasized that there is an urgent need to access to a proper and quick diagnosis and that holistic care is required.

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