CMTC

A world wide non-profit patientorganisation based in the Netherlands.

This is an information brochure about the skin affection called the “van Lohuizen syndrome” of which the Latin name is Cutis Marmorata Telangiectatica Congenita (CMTC).

CMTC
Bitterschoten 15
3831PC Leusden
The Netherlands

tel. +31 33 494 66 71
email: president@cmtc.nl

www.cmtc.nl

What is CMTC?

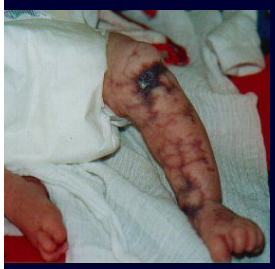
The Dutch children’s doctor Van Lohuizen first described this very rare affection in 1922. It is a skin affection on which the widened veins are glimmering through the skin.
Cutis marmorata means marbled skin. Telangiectatica refers to the abnormal blood veins and congenita means inborn. In general only a part of the skin is affected and the distribution over the body is asymmetric. Which means that one of the sides of the body is seriously affected. The affection seems to appear more with girls than with boys. What the cause of this is is still unknown. A marbled skin like that of a CMTC patient can also appear at a newborn or be influenced by outside factors like cold. An important difference with CMTC is the constant presence of the marbling. The marbling of the skin can reduce in time.

Associated affections

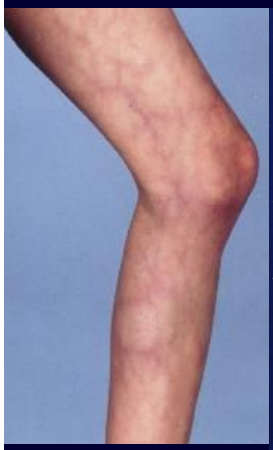
On itself CMTC usually is a rather mild disorder. However at a number of people this affection is described with associated affections. There are many associated affections named to CMTC. From a lot of these affections it is absolutely not sure that there is a connection between CMTC and the named associated affections. With a number of people with CMTC also other skin affections may appear than the marbling of the skin. A nasty side effect is that sometimes sores can appear and that the skin locally can become ‘thin’. This is called atrophy. Another sometimes appearing affection is the asymmetric limbs. Limbs can in first instance be thinner (hypertrophy). In a number of cases glaucoma is also diagnosed.

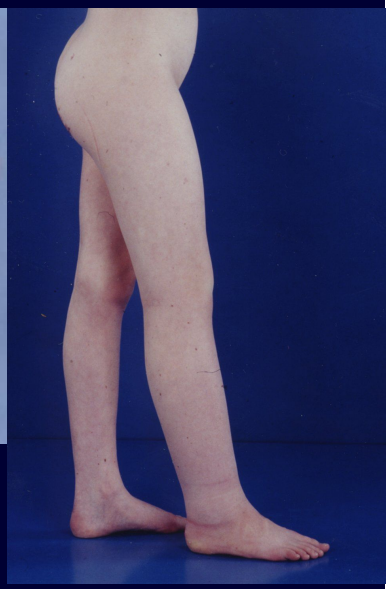
Heredity

Most people with CMTC are the only ones like that in their family. There are very rare mentions in literature of parents who have CMTC just like their children or of brothers and sisters with that affection. At least from literature we know that the chance of repetition of CMTC to a next child is very low. Whether the risk for children of the patient is also low, can’t be said with certainty. About the heredity of CMTC not much is known.



Examples of how the van Lohuizen syndrome can affect the appearance of the skin and the shape of the limbs.





Membership

A membership to our union is only € 25 per year. For this you will eg. gain access to the member area of our website, visit our annual meeting and we offer the opportunity to get in contact with doctors and other patients all over the world.
Of course you can also become a donator. For more information please contact our secretarial service.

Support

Our medical advisors are Prof. dr. A. Oranje (Rotterdam), Dr. M. van Steensel (Maastricht) and Dr. W. van der Schaar.

www.cmtc.nl

Activities

The union is formally founded in January 1997.
We support patients from different countries in all aspects such as free medical examination in the Netherlands. Sofar we have arranged this several times for patients from the USA, Norway and the UK.

At the moment we deploy the following activities:

- Publishing a newsletter every quarter of a year. This newsletter is also distributed among doctors in several academic hospitals and in several countries. The newsletter appears to fulfil in a great need basically because little is known about CMTC. For several times in the past the newsletter took away a piece of uncertainty with some parents.
- Maintaining contacts with both patients and patient unions, domestic or foreign.
- Maintaining (worldwide) contacts with medical specialists.
- Maintaining a website within the worldwide network called the Internet (see web address www.cmtc.nl).
- Organizing meetings for members with as most important goals personal contacts and exchange of information. Usually a medical specialist does a presentation.
- Gather and translate medical articles to a language understandable for non-medical people.

Cooperation with other organizations

We work together with the following organizations:

- Huidfederatie (Skin Federation).
- Kind en Ziekenhuis (Child and Hospital).
- Cliëntenraad Academische Ziekenhuizen (Client Counsil Academic Hospitals).
- VSOP (Union of Cooperating Parents and Patient Organizations for hereditive and inborn affections).
- Genetic Alliance (USA).
- Eurordis (European organisation for rare diseases).
- NORD (National Organization for Rare Disorders, USA).
- Birth Defects Research for Children (USA).
- Vascular Birthmarks Foundation (USA).
- National parent to parent network (USA).