

# SPONSORSHIP FILE



**HELP BRING CMT DISEASE  
INTO THE SPOTLIGHT**



[www.cmt-awareness.com](http://www.cmt-awareness.com)  
[www.ecmtf.org](http://www.ecmtf.org)

Together we are stronger

# EDITORIAL

## The power of collaboration

Since 2016, the main national CMT associations have come together as the European CMT Federation (ECMTF), all working for the same cause. We are united in striving to break through the isolation of those suffering from Charcot-Marie-Tooth, the most widespread group of neuromuscular diseases (1 in 2,500 people worldwide). With support from the associations and their members (patients, families, carers and others...) we provide opportunities for meeting up and discussion. Our basic mission is to share information (news, diagnoses, medical advances), to improve living with the disease and to help progress research. But we can't do this alone and that is why we are turning to you today.

By joining us, you will support our actions and contribute to getting this disease better known and more widely recognized. Beyond this noble cause, for your organization it's about stepping up in the name of solidarity: promoting more widespread information, supporting the scientific challenges and believing in a better world.

We're already counting on your support, because together we are stronger.

**Daniel Tanesse,**  
*President of the ECMTF*

# SUPPORTING THE ECMTF: TAKING PART IN THE FIGHT AGAINST RARE DISEASES



## WHAT IS A RARE DISEASE?

**A rare disease affects a small number of people and so specific problems arise due to this rarity**

There are more than **8,000 rare diseases**, characterized by their low prevalence. Each of them affects **fewer than 1 person in 2,000**.

However, all of these diseases together affect about **2 to 3% of the world's population**. Nearly 80 % of rare diseases are genetic in origin. There is **no recognized cure**.

**«The diseases are rare but the patients are many»**

**How do people live with these diseases?** Once the condition has been diagnosed, or even while **still waiting for the diagnosis**, the patient has to keep on living: facing the problems and challenges of everyday life, enduring the stares of others.

The lack of knowledge about the disease, the absence of any kind of collective representation, sometimes associated with symptoms such as pain or fatigue, which may or may not be visible, often lead to **social exclusion**. The disease is often manifested by **solitude, dropping out of school** for the youngest sufferers, **job loss** for adults, and even depression... Professor Sarnacki – surgeon and vice-president of the national plan for rare diseases (France) – highlights these **markers for concern** which can frequently lead to unstable and even precarious family situations.

## CLOSE-UP ON CMT: CHARCOT-MARIE-TOOTH DISEASE

CMT disease constitutes a group of hereditary genetic neuromuscular conditions which are widespread. They affect about **3 million people globally**, men and women of all ethnic origins and backgrounds.

These neuropathies are **rare, hereditary and they develop slowly**.

Regarding the different types of CMT, **errors and misdiagnosis** are very common and patients often feel that **lack of treatment** is akin to a life sentence.

**This is why the ECMTF is committed** to bringing together patients and doctors to understanding these illnesses better and to obtaining more specific diagnoses and to **helping sufferers lead quality lives**.



# WHAT IS THE ROLE OF THE ECMTF ?



## OUR AIMS:

- Promote swift and **accurate diagnoses, appropriate treatment and care** for those suffering from the Charcot-Marie-Tooth group of diseases (CMT)
- Promote **better access** to accurate and understandable **information for CMT** sufferers, in particular in those European countries lacking a national association
- Promote **awareness and understanding of CMT** among the general public, health authorities and medical professionals
- Finance and **facilitate research into CMT** diseases and encourage collaborative research
- Help **set up CMT patients' associations in European countries** where there are none

The federation is an international non-profit association with a head office in Brussels. Support for the federation is potentially linked to tax reduction advantages, in line with your national regulations.



## NEXT STEPS WHY SUPPORT THE ECMTF & WHAT ARE THE DIRECT ADVANTAGES?



### Your capital value - image:

Through your support, your organization shows that you're **linking action to words**.  
Your CSR communication (Corporate Social Responsibility) **makes sense and becomes a model**.  
Your visibility goes beyond borders and gives you a **European profile**.

### Your capital value - solidarity:

Your teams come together around a **real solidarity project**.  
Your clients and partners see you differently, in **your firm commitment**.  
You all collaborate fully **to raise awareness about public health issues**.

The dynamics of your company will be rooted in feelings of **empathy**.  
No-one is insensitive to human suffering where there are situations of real distress.



# PARTNERSHIP OPTIONS:

## YOUR SUPPORT HELPS US TO:

- Communicate, raise awareness of CMT and reduce diagnosis errors
- Give value to patients and their families as they speak about their experiences
- Help medical science and research progress

Pack/Actions	Research partnership	Events partnership	Communication partnership	General support for the ECMTF
	Min 50 000 €	Min 10 000 €	Min 6 000 €	You decide
<b>Your name on communication tools:</b> brochure, website, posters, roll-up, banner	✓	✓	✓	✓
<b>Support for clinical trials</b>	✓			
<b>Annual Congress:</b> logistic support		✓		
<b>Symposium &amp; Patient Group Supporters:</b> logistic support & print	✓	✓		
<b>Students charity cross</b>		✓		
<b>Infomercial:</b> congress magazines, national general health medias		✓	✓	
<b>Fact sheet for health professionals</b>	✓		✓	
<b>Public relations</b>			✓	
<b>Web serial:</b> "My life with a CMT disease"	✓		✓	
<b>Newsletters:</b> school, health professionals, ...	✓		✓	
<b>Health Professionals Group supporters</b>	✓			
<b>Functional actions:</b> meetings, travel fees, ...				✓



**YOU CAN SHOW YOUR SOLIDARITY AND CONTACT US:**



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