

EUROPEAN STRATEGIES



European ME Alliance

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Developing Solutions for ME in Europe



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What are the ISSUES
and OBSTACLES
in Europe?



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ISSUES &
OBSTACLES?



➤ ***Lack of funding of European ME Research resulting in***

- Too little funding given for research
- Too little biomedical research being carried out
- Lack of a research strategy and/or research focus

➤ ***Vested interests influencing research***

- The absence of registries, accurate standards for research and clinical diagnostics
- Delayed implementation of the latest research



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- ***Lack of education due to the absence of accurate knowledge***
 - Too few clinicians knowledgeable about the disease or its effects on patients' lives
 - Some of those having expertise and support patients are penalised for doing so in some European countries
- ***Slow progress being made compared to urgency of situation***
- ***Continuity in raising awareness and advocacy***



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Leading to poor
outcomes at the
expense of the
patient!



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OUTCOMES?



- ***Misdiagnosis, delayed and missed diagnosis***
- ***Misinformation about the disease***
 - **Poor advice to patients**
 - **Patients disappearing from healthcare systems**
 - ✓ **with little to no care and/or access to support and benefits**
- ***Lack of treatments***
 - **Patients looking (and paying) for magical solutions (that do not exist)**
- ***Prolonged ill-health***



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What is needed?



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A hand with light-colored nail polish is shown from the right, holding a blue marker. The hand is in the process of writing the word 'NEEDS?' in a blue, cursive font on a white rectangular piece of paper. A horizontal blue line has already been drawn across the paper, separating the word from the rest of the page. The entire scene is framed within a large, light-blue circular border.

NEEDS?

- ***Advocacy and raising awareness***
 - Committed European patient organisations working together
- ***European research***
 - European funded and aligned to European healthcare systems
- ***Adequate and sustained funding for biomedical research***
- ***Clinicians to learn about ME***
 - From RESEARCH AND PATIENTS
- ***Young researchers entering the field to build capacity***



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WE CAN
CHANGE
THINGS!

“Things don’t have
to be the way they
are...”

Dr. Ian Gibson
Advisor to UK charity
Invest in ME Research

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**We already have the building blocks,
lets start building in Europe!**



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EUROPEAN
ME
PARTNERS



Patients:

*EMEA
European ME
Alliance*



Clinicians:

*EMECC
European ME
Clinicians Council*



Researchers:

*EMERG
European ME
Research Group*



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WHO IS
EMEA?



➤ *A grouping of European charities and organisations formed in 2008*



➤ *Currently 17 members representing 15 EU countries*

- Belgium
- Czech Republic
- Denmark
- Finland (2)
- France
- Germany
- The Netherlands
- Iceland
- Ireland
- Italy
- Norway
- Spain
- Sweden
- Switzerland
- The United Kingdom (2)

* and in discussion with other countries

➤ *EMEA website: <https://www.euro-me.org>*

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➤ **All EMEA members work to ...**

- Support patients suffering from Myalgic Encephalomyelitis (ME)
- Campaign for appropriate funding of biomedical research into ME
- Advocate for recognition and understanding of this debilitating neurological illness
- Raise awareness of the unmet needs and consequences for patients affected with ME, their families and carers



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WHAT IS
HAPPENING
IN EUROPE!

What are we doing to
overcome the
obstacles and make
progress in ME?

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1. Lack of research funding



- In the absence of adequate funding
 - From national and European research councils
- EMEA members are raising FUNDS themselves
 - To kick-start biomedical research

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2. Vested interests influencing research

- With too few ME researchers and clinicians across the world and little incentives for a career in ME



EMEA created a committed group of researchers

- Creating an atmosphere for sharing knowledge, data and opportunities to collaborate on new ideas and projects
- Encourage researchers to come and work together
- Emphasise international context for research

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- **concentrate on researchers with a real interest in ME**
- **Bring in researchers from other research areas**
- **To agree standards**
- **Provide a platform for biomedical research to public**
- **To move things forward**
 - **Use facilities and expertise available in Europe**
 - **create an environment to expand research across Europe and across the world**
 - **Due to urgency, we need to keep advancing and raise funds ourselves**



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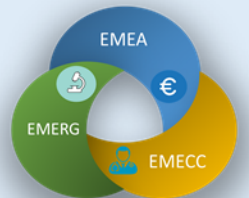
3. Lack of research strategy/focus

**European Centres of Excellence
are developed for ME research hub**

- Using state-of-the-art facilities that already exist and work together
- Enabling continuity of research
- Allowing more possibilities for funding
- Allowing Clinical Trials
- Creating a focal Point for information

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4. Lack of education

- Establish funding for biomedical research
- Encourage reputable researchers to enter field of ME research
- Using the Centre of Excellence hub to provide better information for media, based on research
- Create a clinicians' group to improve and share knowledge
- Better education for the medical profession via more understanding of the disease
- Increase public awareness



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- **Medical students are the future clinicians**
 - ✓ Encourage young, early-career researchers to participate in research, forming a collaborative network for these new researchers
- **The level of education about ME for medical students is limited and narrow**
- **We tackle the problem from within by working with medical schools to create opportunities for medical students to intercalate in research that we are funding**
- **Allows their peers also to become educated and increases knowledge about the disease**



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**Advocacy and
Awareness raising!**



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Taking the issues of ME to EU parliament

EUROPEAN
PARLIAMENT

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In Brussels EMEA members arranged a breakfast meeting for European MEPs with researchers, clinicians and EMEA patient groups



EMEA presented 'Unmet needs in ME' at the MEP Interest Group on Brain, Mind and Pain in the EU Parliament at the meeting on the Value of Treatment (VoT) study from the European Brain Council (EBC).

The video can be watched here:

<https://www.dropbox.com/s/tz6rr1ydnnf7qrc/MEP%20interest%20group%20July%202012th.MOV?dl=0>



Who is EMEA
working with...



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EUROPEAN
PATIENT
COLLABORATION

EMEA is a member of...

European Disability Forum

an umbrella organisation of persons with disabilities that defends

the interests of over 80 million Europeans with disabilities. We

are a unique platform which brings together representative

organisation of persons with disabilities from across Europe.

EDF's objective is to achieve equal opportunities for all men, women and children with disabilities.

UNCRPD, art.25 on health (b)



United Nation Convention on Rights of Persons with Disabilities (UNCRPD)

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender sensitive, including health-related rehabilitation. In particular, States Parties shall:

- b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;**
- d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;**

EMEA is a member of...

European Federation of Neurological Associations

a pan-European umbrella organisation, representing 20 European and International associations across a wide variety of neurological disease areas, working for a better quality of life for people in Europe living with a neurological disorder

- Advocacy
- Awareness
- Empowerment
- Engagement



EFNA

EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

www.efna.net

Advocacy



➤ MEP Interest Group on Brain, Mind and Pain

- An initiative together with the Pain Alliance Europe
- Focussing on the following themes for 2019-2024
 - ✓ Eradicate stigma, isolation and discrimination
 - ✓ Ensure equitable access to treatment, services and supports
 - ✓ Promote patient empowerment for increased involvement and engagements
- aiming to raise awareness of neurological, but also chronic pain and mental health conditions in Europe, underpinned by a strong patient-centric approach intended to prioritise these disorders, encourage research, increase access to innovative treatment, improve quality of life and decrease stigma.
- Place the BMP initiative within the context of global priorities of Non-Communicable Diseases (NCD) and Sustainable Development Goals (SDG).

www.brainmindpain.eu

Awareness

- **Survey of young Europeans with neurological disorders**
 - **These young people (15-35) were chosen because living with a chronic illness they face a number of additional burdens as their peers.**
 - **Often they are unable to complete their education,**
 - **Unable to take a place in the workforce,**
 - **Fear they will not find a romantic partner or**
 - **Have to watch their peers participate in activities they cannot access**
 - **Almost 80% of the respondents were female, with the majority of the responses coming from the below disease areas:**
 - **Multiple Sclerosis (1), Myalgic Encephalomyelitis (2), Chronic Pain (3), Migraine (4)**

Awareness

- Survey of young Europeans with neurological disorders
- Interestingly, all of the aforementioned conditions are largely ‘invisible illnesses’ with symptoms such as pain and fatigue featuring prominently

THE BIGGEST ISSUES

These are the biggest issues facing 18 - 35 year olds living with neurological disorders in Europe today, according to our survey.

2. ISOLATION

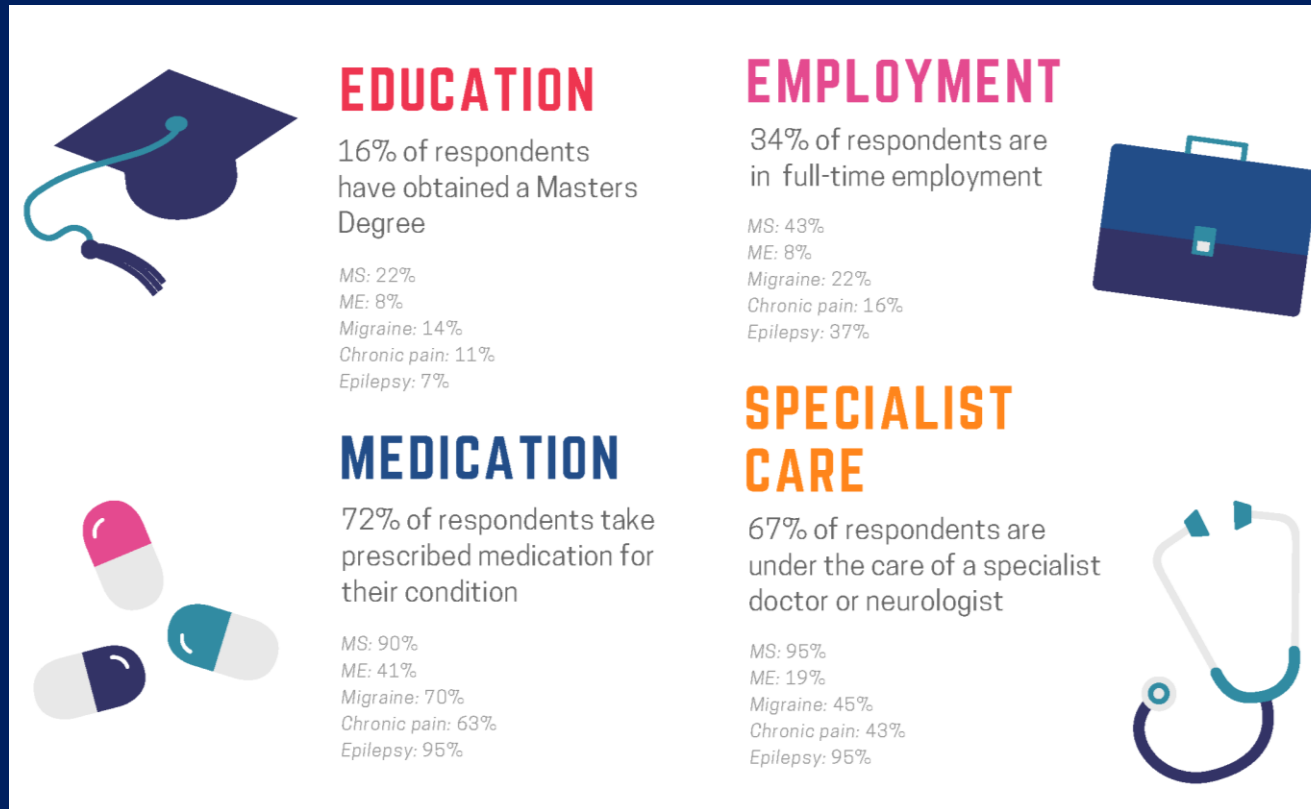
1. ACCESS TO MEDICATION/TREATMENT

STIGMA 3.

The infographic features three numbered items. Item 1, 'ACCESS TO MEDICATION/TREATMENT', is accompanied by a teal first aid kit icon with a white cross. Item 2, 'ISOLATION', is accompanied by a teal icon of a person sitting alone. Item 3, 'STIGMA', is accompanied by a teal icon of a person sitting at a desk with two empty chairs, representing social exclusion.

Awareness

➤ What showed the results for young people with ME?



More information
can be found
here:

<https://www.efna.net/wp-content/uploads/2018/07/EFNAYoungPeopleSurvey.pdf>

https://www.efna.net/wp-content/uploads/2018/07/Data_ME_180704.pdf

Awareness

➤ #BrainLifeGoals

- an EFNA initiative that aims to raise awareness of the impact of neurological disorders



- More information can be found here:

www.efna.net/brainlifegoals/

EMEA brought the campaign to the Invest in ME Research Conference in London



#BrainLifeGoals
Kindness, respect and getting well.



#BrainLifeGoals
For my daughter to have her life back!



#BrainLifeGoals
Patients with ME/CFS are alive but they can't live their lives. As a physician and a researcher my goal is to help them to live and enjoy their lives.

And joined the campaign at the European Academy of Neurology Conference in Oslo

#BrainLifeGoals

FOR ME PATIENTS TO BE TREATED
WITH **RESPECT AND DIGNITY**,
BE TAKEN **SERIOUSLY &**
INCREASE MUCH NEEDED **RESEARCH!**

You can find the video
message here:

www.youtube.com/watch?v=3jnLkaSDSII



We were one of the winners of the #BrainLifeGoals Grant with the project – Aspirations of hope!

- ❖ the creation of a targeted video marketing campaign to raise awareness of the need for research into ME – subtitles in all members languages
- ❖ Patients with ME in Europe will share their stories via video – mentioning their aspirations – their #BrainLifeGoals. The aim is to draw attention to this invisible illness but also look at what is being done – to give hope to patients and carers that something is changing



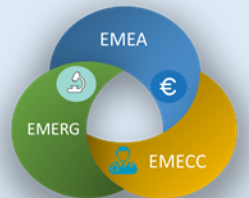
Empowerment to engagement!

- EFNA collaborates with all stakeholders in the field of neurology to improve the quality of life of all those living with brain, mind and pain disorders across the EU, as well as their families and carers
- Being a member is a rewarding experience which has made a real difference for both ME patients and the disease



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In each country,
EMEA members are advocating
and challenging establishment
organisations



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EMEA
MEMBER
INITIATIVES!

What are the EMEA member projects?



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EMA Belgium

joined the Board of the Belgian
Brain Council to strengthen the
ME
patients voice within neurology



EMA Czech

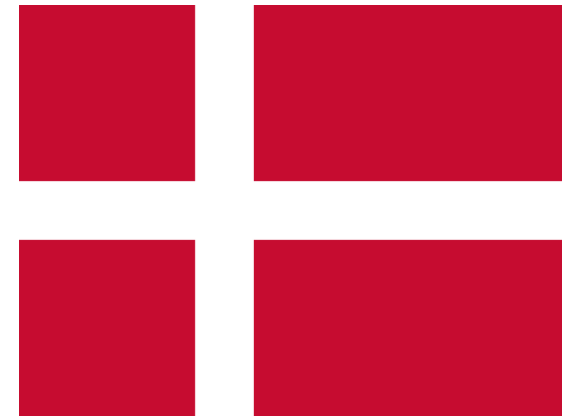
is helping formulate
good
national guidelines



EMEA Denmark

recently helped getting
ME

recognised as
neurological
disease



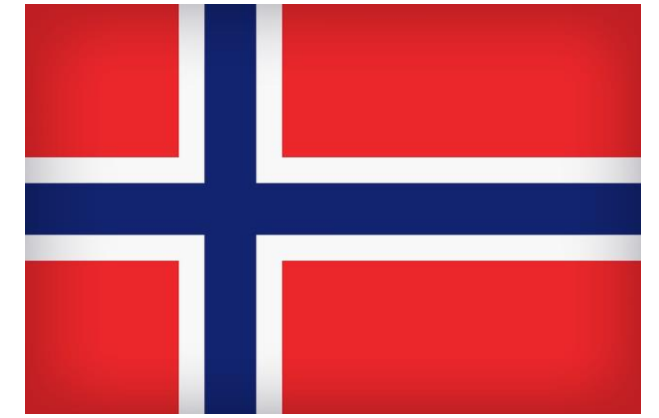
EMEA Finland

has recently helped form a
Parliamentary APPG group
for ME



EMEA Norway

has been working on a survey for severely ill patients, which was presented at the EFNA/EAN Public Awareness Day on ME organised by the Norwegian ME Association at the EAN Conference in Oslo.



EMEA Sweden

is working with health authorities to change how ME is treated and supporting clinicians



EMEA Germany

**We have heard during the day
what
is happening here in Germany.**

EMEA Iceland

**is forming a group to raise awareness of ME
with clinicians in Iceland and forming a
research group**

**and is working with a lawyer on the UN
Rights of Persons with Disabilities**



EMEA UK



- is developing a Centre of Excellence for ME in Norwich



The concept is designed to allow more

- ❖ research opportunities and support
- ❖ improved education and training of healthcare staff



- ❖ by using the facilities in the Norwich Research Park,
- ❖ the opportunity has been created for clinical trials to be carried out
- ❖ a central point for medical education on ME to be established



- has created international young researcher network, the 'Thinking the Future' network

The concept is designed to

- provide an international forum where research into ME can be discussed
- ideas can be generated
- a network built to allow opportunities for those young or early career researchers who are already involved in research into ME, or involved in another research area which may be of relevance to understanding ME



- has established the European ME Clinicians Council and European ME Research Group,
- established international collaborative Colloquiums,
- has set up a clinical fellowship for GPs
- is funding a major clinical trial
- all on top of advocacy in parliament, with Chief Medical Officers and ministers

WASHINGTON

LONDON

NIH
National Institutes
of Health

THINKING
the
FUTURE

Invest in ME
Research

3rd April 2019

28th May 2019

<https://meetings.ninds.nih.gov/Home/Index/22837>

<http://investinme.org/TtF-London2019.shtml>

- **No Isolation - AV1**

This project has been launched

- ❖ **In the UK and Sweden**
- ❖ **With the aim of reducing loneliness and involuntary social isolation**
- ❖ **How?** Through the creation of a physical avatar named AV1.
- ❖ **It shows promising results**
 - **not only for isolation and attending classes remotely with increased school grades and social confidence,**
 - **increases contact with friends and family.**



Make more people aware of AV1, so they know we can help reduce the feeling of isolation and loneliness



European ME Clinicians Council

www.emecc.org

info@emecc.org

A hand with light-colored nail polish holds a blue marker, writing the question 'WHO IS EMECC?' in a large, blue, cursive font on a whiteboard. The whiteboard is set against a dark blue background and is framed by a white circular border. A horizontal blue line is drawn across the whiteboard, separating the question from the rest of the page.

- **a network of European Clinicians**
 - **from different disciplines**
 - **knowledge and expertise in diagnosing and treating patients with ME**
 - **Members from Denmark, Finland, Iceland, Ireland, Italy, Norway, Spain, Sweden and the UK.**



- **crucial for doctors in Europe to**
 - **support each other and work together campaigning for appropriate funding of biomedical research into ME**
 - **act as a focal point for healthcare agencies and doctors wishing to know about the treatments and experiences for ME**



➤ **Their aim is to**

- **combine the available knowledge of experienced clinicians on clinical subtopics related to ME**
 - ✓ **to review the current state of knowledge**
 - ✓ **to present and discuss the latest initiatives**
 - ✓ **encourage collaboration in the field of ME**



- **making it possible to provide**
 - **patients, caregivers, clinicians and researchers with the most up to date information about the disease**

Their work aligns with the US initiative (US Clinicians Council) established by Dr. Lucinda Bateman and Mary Dimmock.





European ME Research Group

www.investinme.org

info@investinme.org

WHO IS
EMERG?



➤ a network of European Researchers

- to create a vision of collaborative research to increase biomedical research into ME
- formed in 2015 initiated by Invest In ME Research
- brought together the foremost European ME researchers, and others, in order
- to establish an understanding of the Aetiology, Pathogenesis and Epidemiology of ME



- **provide a powerful combination with EMEA to**
 - ✓ **campaign, raise awareness,**
 - ✓ **build new research and accumulate data, based on collaboration and sharing of experiences and knowledge, create hypotheses**
 - ✓ **potentially allowing rapid progress in building up a strategy of high-quality research into ME**



The synergy behind EMEA European strategies

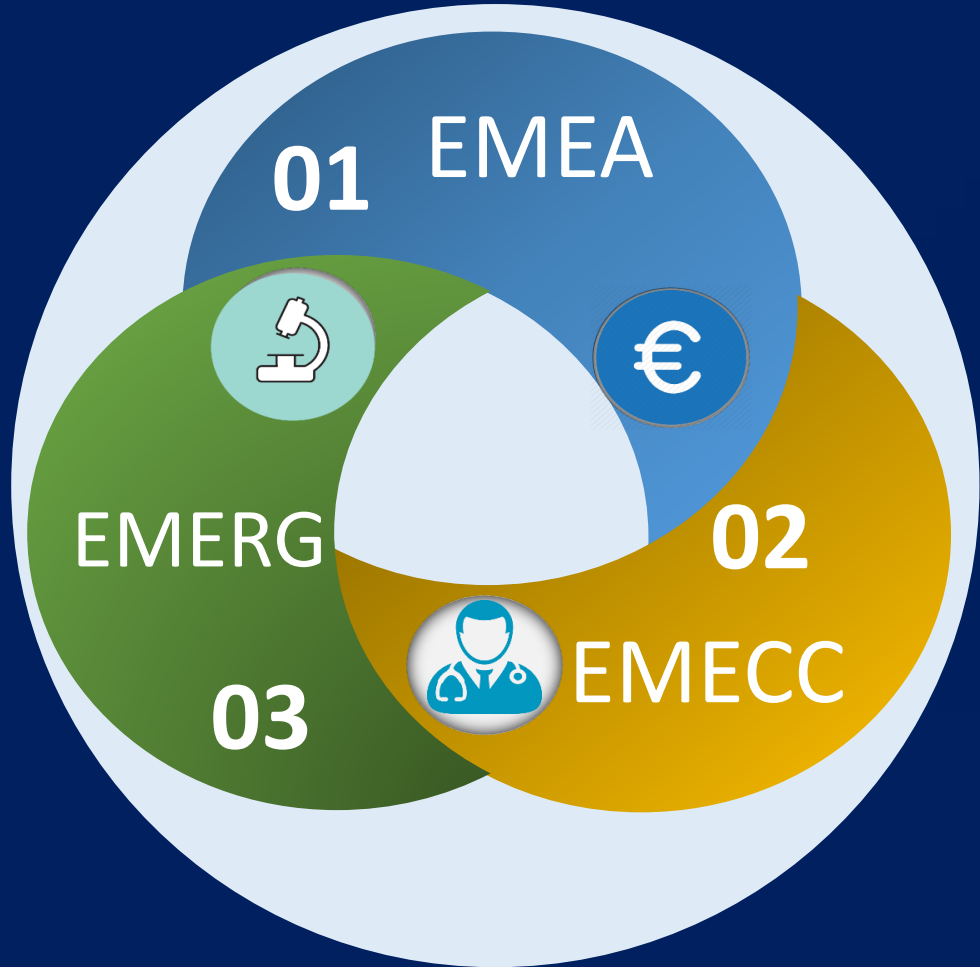


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EMEA European ME Alliance

Patient Organisations

in Europe advocating for people with ME

EMECC

European ME Clinicians Council

A network of experienced ME clinicians

EMERG

European ME Research Group

A collaboration of ideas and skills and facilities to allow European researchers to work together

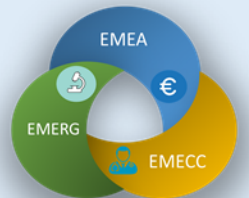
European PCR Collaboration

- up until now - patients, clinicians, researchers - mostly worked in their own area of expertise
- the European PCR Strategy aspires to join these three key stakeholders to enhance
 - ✓ understanding, recognition and awareness,
 - ✓ accurate diagnosis, suitable treatment and care
 - ✓ much needed funding for biomedical research
- this collaboration is vital for the progress in the field of ME



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EMA is working to provide a better quality of life for patients across Europe

Supporting **EMA**, EMECC and **EMERG**
provides a strong European base
for Patient, Clinical and Scientific expertise



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Thank you very much
for listening in name
of all EMEA members!

For more information contact:

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EMEA-email: info@euro-me.org



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EMEA would like to say.

To the patients, their families and carers for their support.

To all researchers, including the pioneers, who've never given up and still continue!

To all clinicians who cared/care for ME patients despite the way they were/are treated and kept/keep believing in the patient.

To every volunteer supporting EMEA and its members, raising awareness and money, advocating or being there for a patient in need and doing so much more.

To all EMEA members and organisations they're working with and anyone we might unwillingly have forgotten,

THANK YOU VERY MUCH!



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