

**WE**  
**ME**

*A Community and ME*

# **A COMMUNITY.....and ME**

It seems almost everybody knows somebody who has myalgic encephalomyelitis (ME, also known as ME/CFS) – a disease that appears to be more prevalent nowadays, especially due to the awareness raised by social media.

But how much do people really know about the disease, the effects on families and patients, the effects on the economy and the issues that are faced?

The community is the bedrock of society – different people doing different things, supporting each other in various ways - even when something comes along to upset the balance and harmony of life. At least, that is what a community should be.

What happens when such an upset comes to somebody in the community – how does the community react?

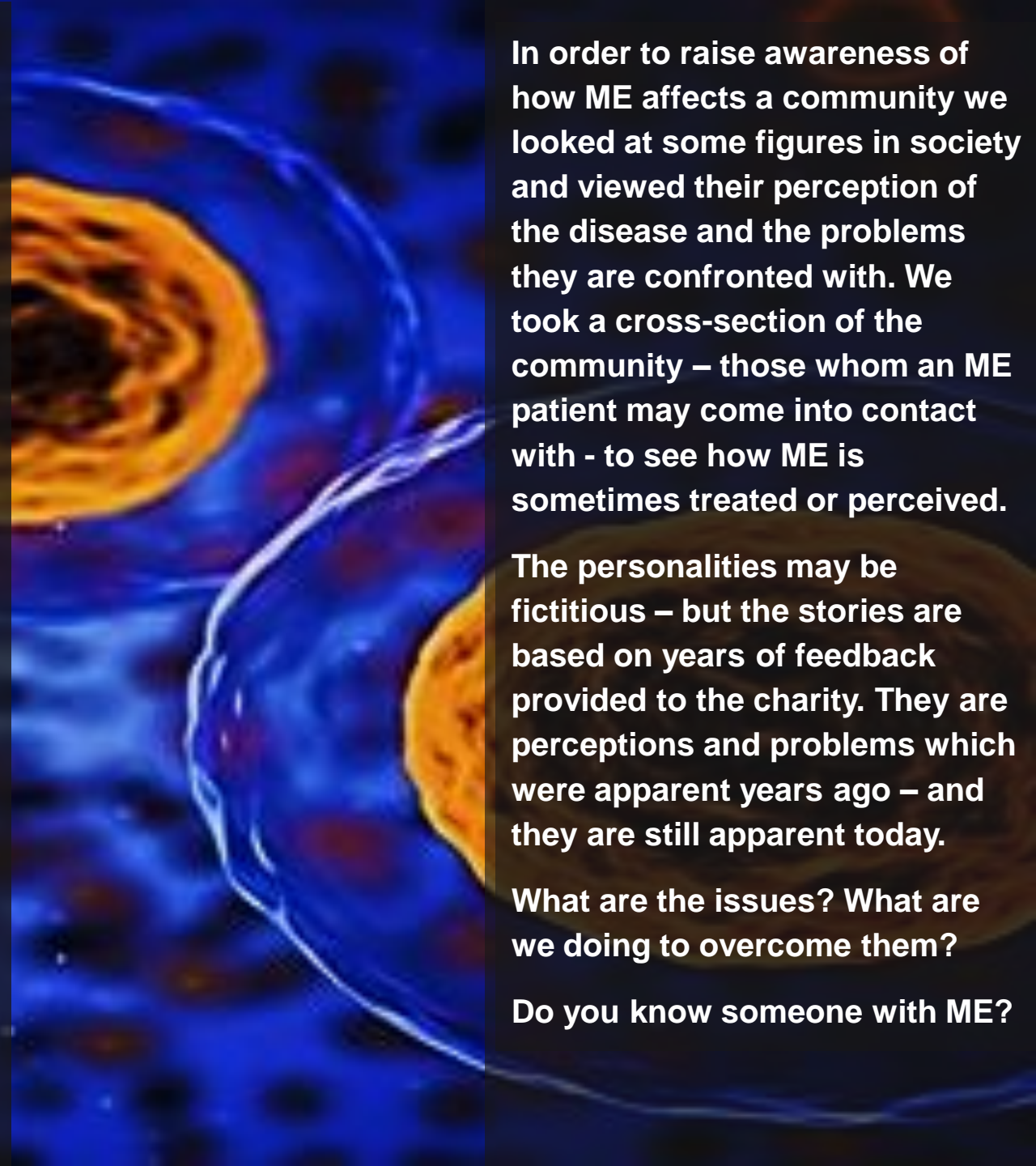
A condition such as ME presents not only a challenge to the patient who receives the diagnosis, nor only to the family where a child or partner contracts the illness. It tests the values and the fabric of a community. The reactions of the community describe how prepared or willing it is to overcome the challenges and support the patient with ME.

In order to raise awareness of how ME affects a community we looked at some figures in society and viewed their perception of the disease and the problems they are confronted with. We took a cross-section of the community – those whom an ME patient may come into contact with - to see how ME is sometimes treated or perceived.

The personalities may be fictitious – but the stories are based on years of feedback provided to the charity. They are perceptions and problems which were apparent years ago – and they are still apparent today.

What are the issues? What are we doing to overcome them?

Do you know someone with ME?





# WHAT IS ME?

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## **What is ME?**

ME is a multisystem, complex, acquired illness with symptoms related mainly to the dysfunction of the brain, gastro-intestinal, immune, endocrine and cardiac systems. ME has been classified as a neurological disorder in the World Health Organisation's International Classification of Diseases since 1969.

The Chief Medical Officer's Report issued in January 2002, recognised that ME "should be classed as a chronic condition with long term effects on health, alongside other illnesses such as multiple sclerosis and motor neurone disease". Similarly the Institute of Medicine report of 2015 stated that ME is "a serious, chronic, complex, multisystem disease that frequently and dramatically limits the activities of affected patients."

## **Who gets ME?**

Anyone can get ME. It is more common in women than in men. In children the ratio between boys and girls tends to be the same up until puberty after which time it seems to be more common in girls than in boys. However, epidemiological data is lacking and further difficulties in assessing the research data is caused by use of widely differing criteria for research or diagnosis.

## **How many people have ME?**

Estimates vary between 0.11% and 2.6% of the population depending on the criteria used. In the UK the most often cited prevalence figure is 0.4% or 200 000 to 250 000 people of which 25 000 are thought to be children. To date there is no known specific medical diagnostic test to determine or confirm a correct diagnosis nor is there any specific treatment for ME.



# WHAT IS ME?

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## **What are the typical symptoms of ME?**

Symptoms include overwhelming post-exertional malaise (PEM) from mental or physical activity; dysfunctional sleep; pain; problems with memory; sensitivity to light, touch and sound; problems with standing and balance; problems with body temperature and weight; and recurrent flu-like symptoms; that persist for at least six months in adults; or three months in children (Carruthers et al, 2003).

## **Is ME contagious or inherited?**

There have been several documented outbreaks of ME but evidence of person to person transmission is lacking. ME is more common in some families pointing to a genetic component but there is no evidence of ME being inherited as such.

## **What medications and treatments are available?**

There are no MHRA (Medicines and Healthcare Products Regulatory Agency) or FDA (U.S. Food and Drug Administration) approved drugs to treat ME yet. Treatment is based on managing symptoms and avoiding over-exertion. Patients find pacing mental and physical activities most beneficial.

Drugs such as Ampligen (immune modulator), Rituxan (biologic) and Valcyte (antiviral) have been trialled but they have not proven to be successful.



# WHAT IS ME?

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## **Can I donate blood if I have an ME diagnosis?**

As the cause of ME is unknown and it often follows an infectious episode with relapsing and remitting nature patients with a diagnosis of ME/PVFS/CFS are permanently excluded from donating blood. This applies to even those patients who say they have recovered.

## **Can ME be cured?**

Currently there is no cure for ME and treatment is based on managing the condition and providing symptom relief. It has been generally accepted that young people with ME have a more favourable prognosis than adults. Progress in developing research to find a cure or effective treatments is a main objective of Invest in ME Research.

## **Why is ME so difficult to diagnose?**

Diagnosing ME can be a challenging process as there is no single laboratory test yet available to prove or rule out ME. A careful history taking is important and if the symptoms or test results are attributable to another active disease process ME should be ruled out. Conditions such as major depressive disorder, MS, eating disorders, bipolar disorder, thyroid disorders, Addison's disease and some cancers for example can present themselves with symptoms such as fatigue, sleep disturbance, pain and cognitive problems and should be ruled out before a diagnosis of ME is made. If another active disease process is well under control and the patient still has symptoms that fulfil ME criteria then an ME diagnosis can be made.



# RESEARCH SUMMARY

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## **What is the status of research into ME?**

There are over 9000 research papers published on ME/CFS but the studies are often small or the reports show conflicting results. This is complicated by lack of specific biomarkers and criteria to define the illness.

There have been very few clinical trials and they are desperately needed to test treatments in a scientific manner to allow doctors to make informed treatment decisions.

It is now generally agreed that there is evidence of disturbance in the central and autonomic nervous system, energy metabolism and the immune system. Studies into the microbiome and genetics are promising too but need more research.

The technology has moved on vastly so it is difficult to make comparisons between old and current research.

The questions going forward need to address the cause of the symptoms, the reason for abnormalities in the various systems and whether there is a connection between these systems.

## **From Quadram Institute Bioscience**

" The causes of ME/CFS aren't known, and there are no effective treatments.

Symptoms range in severity, and there are no easily identifiable biomarkers of the condition, so diagnosis is sometimes difficult.

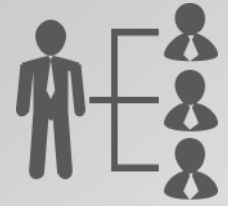
There is a pressing need for biomedical research into ME, and within the Quadram Institute and the wider Norwich Research Park we have the interdisciplinary expertise needed to better understand this complex disease."

GP



CONSULTANT

HOSPITAL CEO



SOCIAL WORKER



TEACHER



I KNOW SOMEONE WITH ME



MP



COMPANY CEO



RESEARCHER

CASE STUDIES



CHARITY

# I AM A GP

I am a doctor. I consider that I try to help my patients who have ME although I know that there are many GPs who do not believe in the illness. Yet we all see how disabled these patients are. There is little we can do.

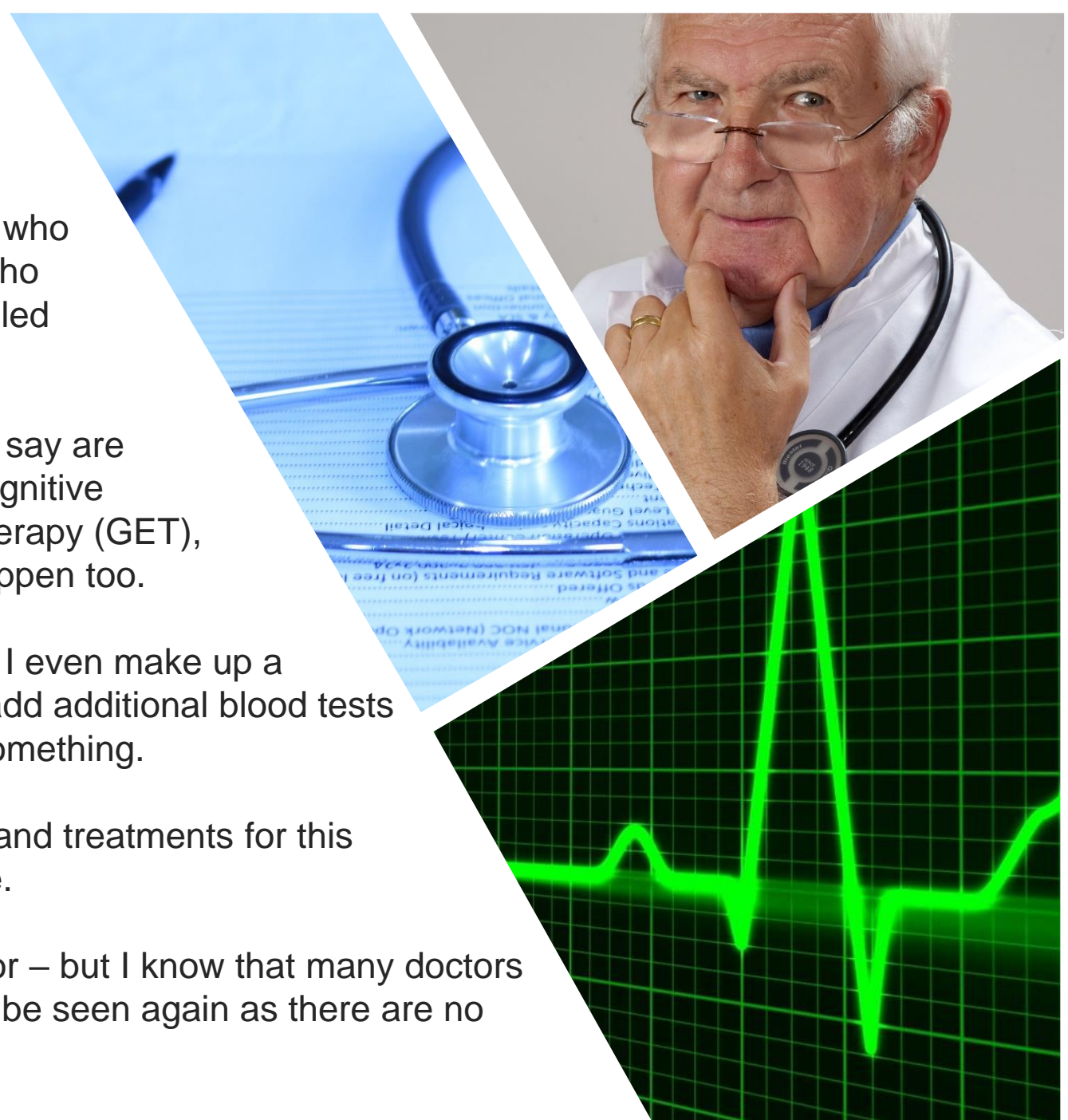
We follow NICE guidelines – which my patients often say are unhelpful as they recommend treatments such as Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET), that patients say make them worse. I can see this happen too.

I run the blood tests that I am allowed to. Sometimes I even make up a “concern” about the patient’s condition so that I can add additional blood tests that are not officially recommended, but may show something.

What else can I do?

We need research that can develop diagnostic tests and treatments for this condition. I do not have time myself to research more.

I hope my patients see me as a compassionate doctor – but I know that many doctors will dismiss this disease and patients will often never be seen again as there are no treatments available.







# I AM A CONSULTANT

I have patients with ME.

ME is not my speciality, there is no specialist consultant service for ME at the hospital, or any hospital that I know of. GPs in my area refer patients to me at the hospital.

I do not know much about the condition and I just try to treat the symptoms presented. I have twenty minutes to see the patient and there is little I can offer other than reassurance. There are no evidence-based treatments and the diagnosis may be confirmed, or maybe I say it is fibromyalgia if the patient has widespread pain, as patients often feel better having a definite diagnosis. The neurologists at the hospital generally do not deal with the condition as they do not see it as neurological. A university hospital would be the best place to establish some specialist consultancy but this is not going to happen here.

# I AM A PAEDIATRICIAN

## I SEE YOUNG PEOPLE WITH M E



I am a paediatrician at the hospital and children are referred to my department by GPs who suspect ME but want us to determine the cause of the child's condition. I see the child separately from the parents and look for other possibilities that may have been overlooked. When I initially assess a patient, I must be alert to the potential emotional dimensions of the illness including family dynamics, which I must sensitively explore. Others in my profession have suggested alternative reasons, such as fabricated or induced illness (FII) or similar diagnoses. It is hard to determine what is wrong as the tests that we make are often inconclusive. There are no treatments we can give but our position is to recommend Cognitive Behavioural Therapy (CBT) and/or Graded Exercise Therapy (GET) and we refer the child to CAMHS (Child and Adolescent Mental Health Services).

# I AM A HOSPITAL CEO

I run a hospital. We have no clinical service for ME patients, as such, as my consultants at the hospital do not wish to establish such a service.

I am told there is either no such disease as ME or that it is so poorly understood that it would not be possible to maintain a service for patients.

However, some of our consultants do see ME patients who are referred via their GP.

If we create a service for these patients then we would also have to meet and maintain targets for the service - problematic.

The cost also means that we have to reduce funding elsewhere.

ME is not a priority for this hospital. Better to let Clinical Commissioning Groups (CCG) cope with this.





# I AM A TEACHER

I am a teacher. In my class we have a child who has been long term ill with ME. It has been difficult for this child to keep up to date with school work and it has not been possible to maintain any regular attendance.

The parents are trying to find ways to help but it has become difficult and the child now has a few hours a week of home tuition.

We have no knowledge of this disease and do not have the resources to give special treatment. The child has lost so much of the curriculum compared to others in the class and I cannot see how she can be integrated back into the class.

We have another child in the school with ME – it is the same for him. I have heard of teachers who have become ill with ME.

It is a difficult illness to understand and, as teachers, we do not have enough time to devote to those who are not regularly attending. It is difficult for everyone.

# I AM A SOCIAL WORKER

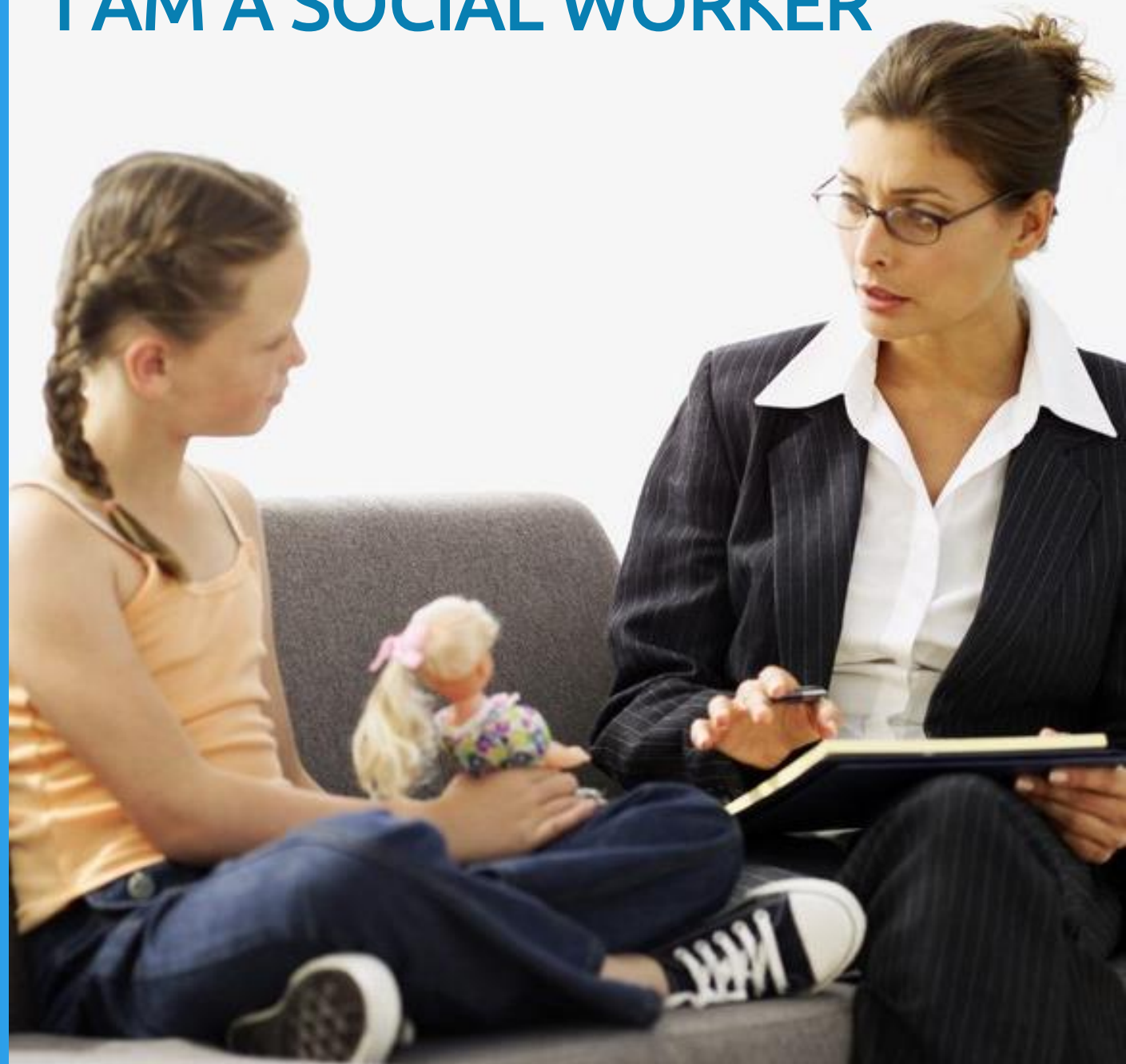
I am a social worker and I am often dealing with young children with ME in this district. I have to be thorough as I am responsible for making the right assessments. I see children with ME to assess if they are being adequately cared for.

I do not know much about ME but the children I see look tired and ill and the doctor has said they can find nothing wrong with them.

The parents have refused to let their child continue the treatment recommended by the doctor – Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET).

That troubles me. If they really wish to see their child get better and if these treatments are suggested by the doctor then why would the parents not want the child to get better?

I interview the child and I have to confirm whether the child is at risk of harm.



# I WORK in BENEFITS

I work as an assessor in a company that is subcontracted to perform interviews of claimants for welfare benefits. We see a fair few claimants who say they have ME.

I have been given some training on ME but I do not know that much about the condition, other than what the person says in the interview. I am not required to.

My job is to measure function and the capability of the person seeking to obtain welfare benefits. I test the client's ability to perform daily tasks. The tests are very general and do not depend on the condition being tested.

In my department we have targets that we are expected to meet so the assessment is a numbers game rather than a genuine evaluation of daily function of the claimant. Also we seek to enact the guidelines passed down from the Department of Work and Pensions.

We make it clear that it is not us who make the judgement on whether anyone receives a welfare benefit. But, of course, my evaluation is important. Some disagree with the judgement and appeal. Not my concern.

We have targets to achieve - and the contract is lucrative for the company.





# I AM AN EMPLOYER

I am head of a department in an IT company.

We employ someone with ME.

A very capable worker but he has now been ill with ME for a year. Sometimes he comes in to work but often cannot complete a full day of work.

I do not know what to do to help.

The Chief Medical Officer (CMO) at the company has asked him to undergo a course of CBT and GET but the employee says that these therapies are making them worse.

The CMO is adamant that the course of therapy has to be completed and our company policy has to be maintained.

I don't know what to make of it.

The employee has sought union support and the situation has become very acrimonious.

The case is now with the HR department and our insurance company.

# I AM AN MP

I am a Member of Parliament and I have constituents with ME. Many have had the condition for several years and I am often asked for help in getting research started or to lobby for services or help with challenging benefits decisions.

I hear the same complaints and there seems little I can do about it.

I pass on the requests to the Secretary of State for Health.

The replies do not achieve much – often repeating the same line from civil servants that the Medical Research Council is responsible for funding research and the government recognises ME as a neurological condition. My constituents are dissatisfied with the answers.

I pass concerns of bias to the Science Select Committee but nothing ever seems to be done.

I do not take on each case but will occasionally send in a letter to the local hospital to ask about services. Generally, there seems to be no interest in doing anything about this.

Lack of resources and quotes about NICE Guidelines are returned. The hospital itself is hard-pressed to achieve its targets, set by the government. No ring-fenced funding for research exists and no research is happening for ME at the nearby university.

Doctors whom I have met do not believe in this condition and regularly send patients home with some advice that they have gained from NICE. What more can I do?





# I am a Researcher

I am a researcher and we have been looking into research into ME. However, it is difficult to get interest in our institute as there seems to be no funding available for this disease and a lack of interested and ME-knowledgeable consultants to work with.

Also, it is not often that we get interest from university students to enter this field as they see no career in it, due mainly to the perception of ME and due to the lack of funding.

We would like to research ME as we feel it is an interesting area of research and also a major health problem. But the grants boards on the research councils do not seem willing to approve funding.

My grant applications have been declined – even though a majority of the review panel scored our applications highly.

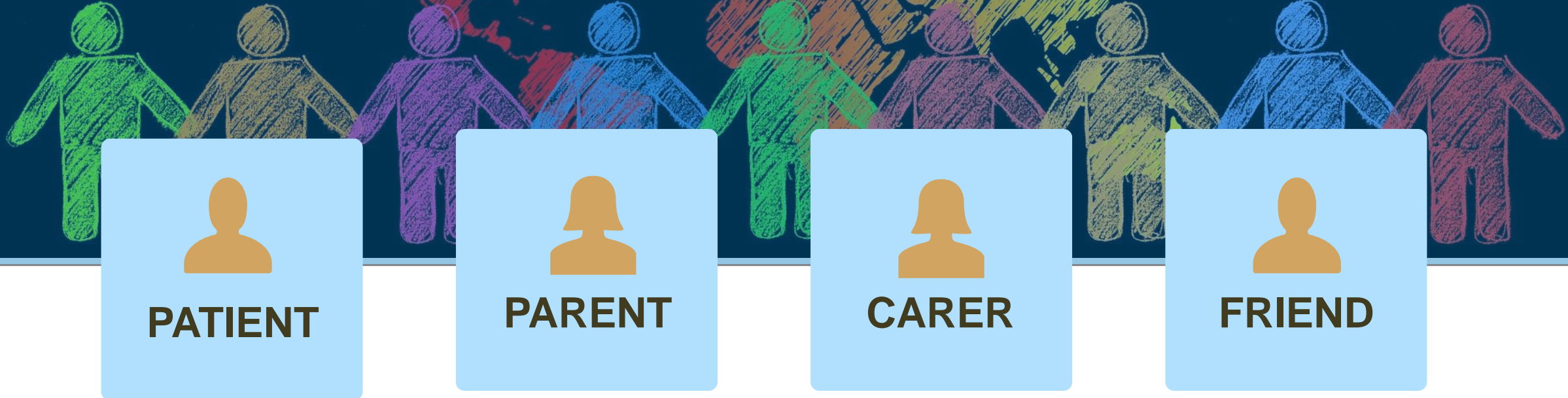
It takes a great deal of effort and time for the university to enter an application so when research applications are likely to be met with a negative response then it is not a good use of our time.

It is strange, too, that our applications have been rejected as the research council has made ME a highlighted research area. The comparatively small amount of funding provided seems to have gone to psychosomatic research with no benefit for patients.

Charity support seems to be the only way to enable biomedical research into ME.



# HOW IT IS REAL LIFE EXPERIENCES of PEOPLE AFFECTED BY ME



The examples of how the community sees ME in the previous pages were based on fictitious characters – though the scenarios were real and the issues raised are those that exist, for the main part.

The following pages contain real life stories – from people in the community who experience this disease every day, from different aspects of life. These are people who know ME, who live ME, who suffer from ME....

# SUSANNA, a Person with ME

“As you will know I have M.E as well as other things! But maybe all those things are part of a whole condition. The point is no one really knows....and how can anyone get better if they don't know the root cause of why they have got so sick.

Those that are suffering need an answer, to then get appropriate and effective treatment, and get better from this life changing, life limiting, cruel illness.

I want to get better, and I've tried so many things but I still remain firmly living a life dominated by symptoms.

Biomedical research in my mind is the only way forward, and unfortunately because it's not being funded by the government, here I am selling Christmas garlands over the year of 2019 to fill peoples homes with festive joy and also raise precious funds for Invest in ME Research. ”



# A Person with ME

“I have had M.E. for almost four years and am quite severely affected. I am housebound most of the time and often bedbound.

I was previously a 'high flyer' (my neurologists' words) and a civil servant with a social work background. Due to my illness I am no longer able to work, and have just been through the very painful process of applying for ill health retirement.

My pension provider has a two tier system for pension awards in the circumstance of ill health retirement. I have undergone five medical assessments during the process and have been assessed as permanently incapacitated in terms of employment. However, as I have not completed the treatment, as recommended in the NICE guidelines, I cannot obtain the higher rate pension. The treatment namely being Cognitive Behavioural Therapy (**CBT**) and Graded Exercise Therapy (**GET**).

I have engaged with the specialist M.E. service but was unable to continue as attending sessions made me more unwell. I tried CBT through my local mental health service, attending three out of six sessions, this made me more unwell and put me back into bed for weeks.

I am in receipt of the highest rate of both ESA and PIPS. These were both awarded following the first medical assessment, which I understand is not the position for far too many M.E. sufferers.

I have taken my ill health retirement case to appeal within my pension service.

The position of the original decision not to award me the higher rate pension has been upheld on the grounds that I have not completed CBT and GET.

My pension provider will now escalate my appeal to stage two of the process. However, the decision makes it clear that, in order to succeed, I need to prove that I have completed CBT and GET.



# A Patient.....continued

***“I am faced with a position that is unfair and takes away any right I have not to undergo treatment that exacerbates my illness.***

I have had support from my union, however they aren't familiar with the fight that M.E. suffers like myself face.

I have previously had a life where I travelled up and down the country for my career, helping to make a difference in the lives of vulnerable children. I had authority and was very much a professional.

I have always worked within the public sector, both local and central government.

I had a lively social life, always on the go with my partner and family.

Now my life revolves around my bedroom.

I rely on pillows, blackout curtains and strong medication to try and control my pain.

If I journey out, it is to visit my G.P. which takes around three hours to get me ready for, with lots and lots of assistance from my wife, who is also my carer and carer to our 18 year old disabled son.

I often find it difficult to construct challenges around my illness as I simply can't find the words due to my diminished cognitive functioning.

This is one of the hardest symptoms to deal with. The loss of intellect. It's in there somewhere, I'm in there somewhere, but I just can't get the words to make sense.

It is imperative that someone listens to our voices and I am so thankful for your determination in challenging the medical profession around our treatment options.

It will probably be too late to make any difference to my case.

I hope that in the future no one will be penalised for not undergoing treatment that is harmful to their health .... that CBT and GET will be removed from the (NICE) guidelines.”



# WE ARE A FAMILY

“Maddie, our cousin and sister, is 19 years' old and has suffered with progressively worse M.E. for the past 7 years. Her poor health led to her having to give up school shortly before her GCSEs and she is now bedridden, tube-fed and sleeps for 23 hours a day.

Maddie is not alone in suffering this way. It's estimated that around 250,000 people in the UK have M.E., and around 25% of those are affected severely.

We miss our funny, happy, energetic cousin and sister Maddie, we want her to recover so we can have her back laughing and joking with us. The only way for this to happen is to invest into M.E. research so we are raising money for Invest in ME Research by completing the Three Peaks Challenge.

We are walking for Maddie because she can't ...”



# I AM A PARENT and CARER



I am Claire – parent and carer for Amy.

Our beautiful Amy is still fighting this devastating illness and although we have been lucky enough to have made improvements to her environment, she is still extremely limited in how she is able to live her life, every day.

Understanding, help, education and awareness for Amy, for us, and for every person and family living with this terrible illness is still so very desperately needed, and severely lacking.

The truth is, "we" (parents, people, doctors, scientists, biochemists, psychologists, neurologists, experts & specialists) still 'don't know' what causes M.E., what to do, or how to treat it. We are still in the dark. Until we do know, millions of lives are on hold. This is why research is urgently needed.

*Claire ran the Royal Parks Half Marathon to raise awareness of ME and funds for research.*

# A FRIEND of a FRIEND WITH A SON WITH ME

My friend's 16 year old son Alex has had severe Myalgic Encephalomyelitis (M.E) for 5 years, since he was just 11 years old. The impact on his son has been devastating.

My friend's once happy, sociable and very active son now suffers with a multitude of symptoms including unrelenting and debilitating physical & mental fatigue, severe cognitive impairment, insomnia & sleep reversal, pain and orthostatic intolerance.

He is bed bound at least 75% of the time and reliant on mobility equipment including a stair lift and powered wheelchair to move around safely.

Alex has been too ill for any education since 2014 (all of his secondary school years) and has lost all of his friends. Although we hope he won't always be this ill, we have no idea what the future holds for him.

*Arry rode the Mountain Mayhem, the longest running 24 hour mountain bike endurance event in the world, to fundraise for Invest in ME Research and to raise awareness of the condition.*





# MY FRIEND

My name is Mike Harley. One of my oldest friends, Ian, has been suffering from ME for over 9 years and has been unable to work or lead a normal life.

As with many people who have ME, a full recovery isn't by any means guaranteed especially where lack of, or mis-diagnosis of the condition is rife and where governments continually fail to support clinical trials and proper research. I'm attempting to raise funds and awareness of the disease and funds for the charity Invest In ME Research who are developing a strategy of high-quality biomedical research in a Centre of Excellence for ME.

My challenge in doing this is by running a marathon in every EU country (currently 28 in total).

It is estimated that over 250,000 people in the UK suffer from ME and this includes 25,000 children. ME is the main reason for child school absence in the UK and the numbers above are old estimations, it's likely that many more remain undiagnosed with the illness.

In travelling to many European countries and meeting patients and families affected by the disease I have seen the real effects of ME and how lives are ruined.

Working with the charity I am trying to do something about this terrible disease – for my friend, and for millions of others.



## A CHILD WITH ME

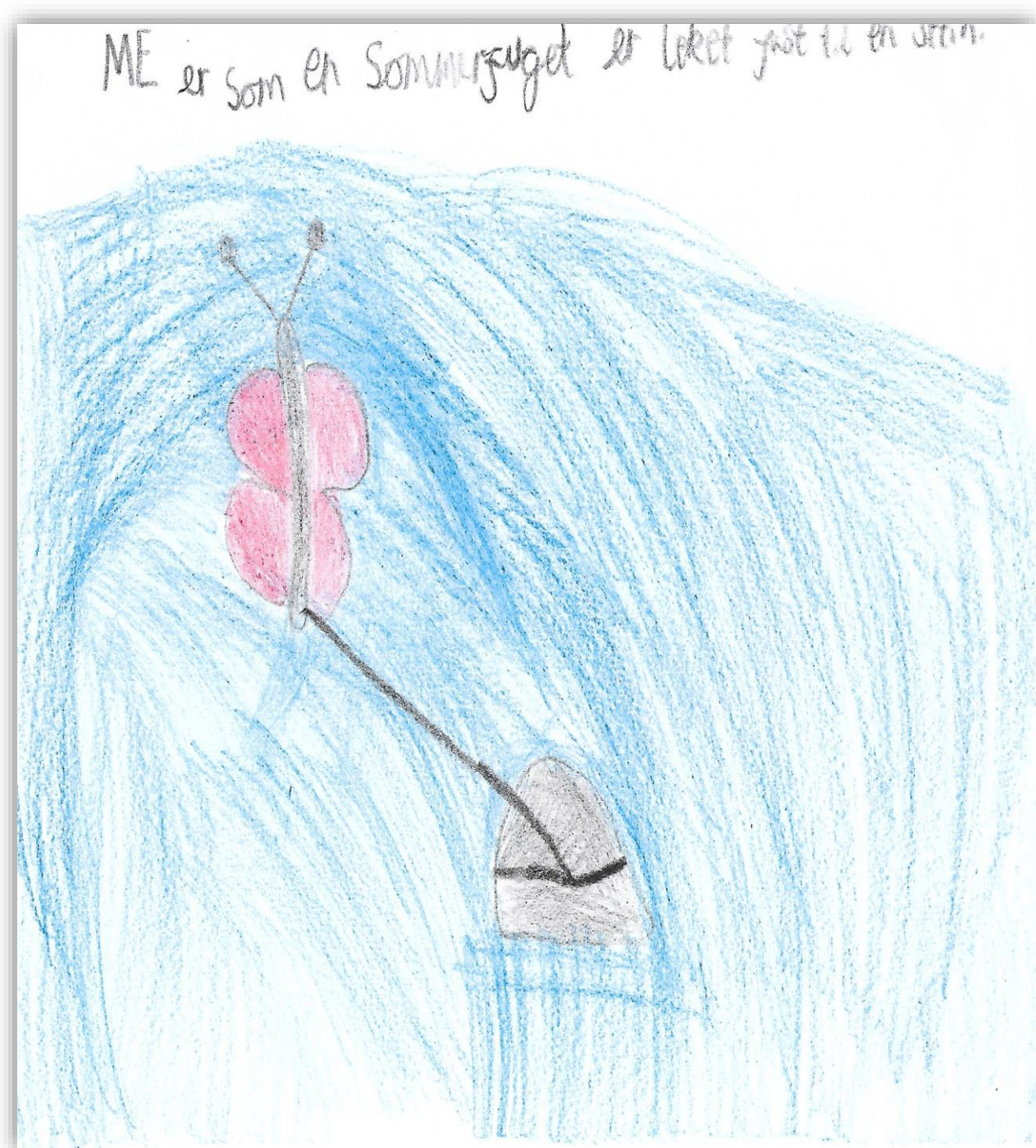
# ME is like a butterfly chained to a stone

Emma is from Norway and was nine years old when she drew the picture on this page. She had had ME for over three years at the time.

The caption reads "ME is like a butterfly chained to a stone"

ME knows no geographical boundaries – it affects all ages.

The image perhaps says more than a long scientific article about the consequences of this disease.





**Some ME patients you will not see.**

**Locked away in dark rooms, unable to tolerate light, sounds, touch or smells  
– excluded from the healthcare system, forgotten by society, totally reliant on a parent, or partner or carer  
– or perhaps just themselves.**

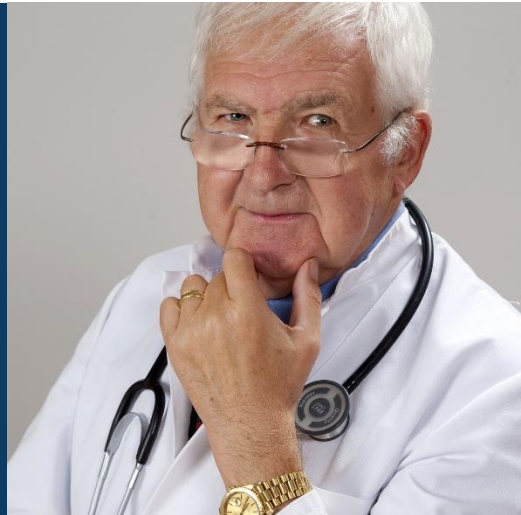
**The ugly truth of severe ME – invisible to the world, oblivious to governments and chief medical officers, unresearched, forgotten.**

**Discrimination by neglect from those responsible for healthcare**

# ISSUES with ME

## GP

- GP disbelief
- NICE guideline constraints
- Limited interventions or treatments
- No diagnostic test



## HOSPITAL

- No specialism in ME
- Diagnosis uncertain
- No treatments
- Lack of knowledge
- Care of child



## TEACHER

- Limited resources
- Difficult to maintain contact
- Lack of knowledge



## EMPLOYER

- Company policy



# **ISSUES with ME**

## **SOCIAL WORKER**

- Lack of understanding of ME and effects on family
- Suspicion of parents



## **BENEFITS**

- Little knowledge of effects of ME
- Targets to achieve
- Simplistic decisions



## **MP**

- Limited power or influence
- DOH/Ministry apathy



## **RESEARCHER**

- Little funding
- No strategy
- Not priority





# ISSUES with ME

## PARENT

- Facing disbelief and ignorance from social services, schools, GP
- Isolation, long term effects
- Own career affected



## CHILD

- Isolation
- Loss of education
- Effect on family
- Consequences into adulthood



## ADULT PATIENT

- Lack of any treatment
- No income
- Loss of career
- Stress from fighting DWP
- Disbelief from family
- Isolation



## CARER

- Feeling helpless
- Anger at failed system
- Lack of support



# IGNORANCE



The basis of mostly all of the issues stems from ignorance.

This ignorance is either due to misinformation – either mendacious in nature (produced and perpetuated to enhance careers, or organisational influence or for financial gain) or from lack of knowledge about ME.

Ignorance drives the false view of ME and ineffectual therapies being forced onto patients. This then cascades to other areas such as benefits decisions, puerile media commentary, biased or flawed medical curricula, incorrect perception by the public.

The ignorance about ME itself is allowed to thrive because there is lacking evidence to convince those in influential positions to act.

# GOING FORWARD



The lack of evidence is attributable to the lack of proper research – itself caused by lack of funding, again based on ignorance (mendacious or otherwise).

Many of the issues surrounding ME today could have been resolved, in part or in full, if recommendations from the Chief Medical Officer's Report (CMO) on ME had been implemented.

That report was made in 2002 – almost two decades ago – and to date none of those recommendations can be said to have been realised.

The CMO report made recommendations regarding Recognition and definition of the illness, Treatment and care, Health service planning, Education and awareness and Research.

Research is the key to changing the future for people with ME.



# **An Overhaul of the Existing Infrastructure for ME is Urgently Required**

*The recommendations from the CMO Report of 2002 must be reviewed, brought up to date and implemented where they will benefit people with ME.*

*This would facilitate the implementation of solutions for many of the problem areas with ME.*

*It would also force the CMOs of UK to act in unison and more responsibly in promoting awareness and research and treatment of this disease.*

**Funding of biomedical research needs to be provided according to a strategic plan based on a Centre of Excellence for ME model**

*A beginning in developing a Centre of Excellence for ME has been made in Norwich Research Park.*

*This needs to be funded further and development must be sustained.*

**GOING FORWARD**



***“Invest in ME Research proposed last year that ring-fenced funding of at least **£20 million a year for five years** should be allocated for biomedical research into ME.***

***This £100 million would be a beginning to end all of the years of suffering of people with ME and give hope for the future. It would encourage new researchers to enter the field. This is a relatively small amount.”***

***from “INVEST in ME RESEARCH - THE DEBATE IS OVER  
INACTION for ME IS NOT AN OPTION  
GIVE ME PATIENTS A FUTURE 2019”***

**UK Parliamentary Debate on ME 2019**

**[www.investinme.org/pdeb19](http://www.investinme.org/pdeb19)**



# Research – the Key to Progress



Biomedical research is the key to future progress.

Nothing else matters if research is not performed

Without research – there are no cures, no treatments, no clinical expertise, no media attention, false information, more suffering, more false careers maintained.

Research leads to better education, more informed doctors and social workers and research community and hospital staff and teachers – and even government agencies and their subcontracted benefits assessors.

Research and better education empowers us to advocate from the basis of knowledge and evidence. Invest in ME Research has developed this model to bring about change.

All of the issues mentioned above can be grouped, and resolved in this way.



# WHAT ARE WE DOING?

UK Charity Invest in ME Research is proposing solutions.

The charity has made real progress in setting up key building blocks that have created sustainable and permanent change in how ME is researched and treated.

The charity is finding, funding and facilitating biomedical research into ME in a variety of ways and is focused on -

- creating solid foundations for a research programme on ME
- solving scientific questions relating to ME
- finding treatments that are based on research evidence
- raising standards on all levels of patient care
- facilitating European and international collaboration



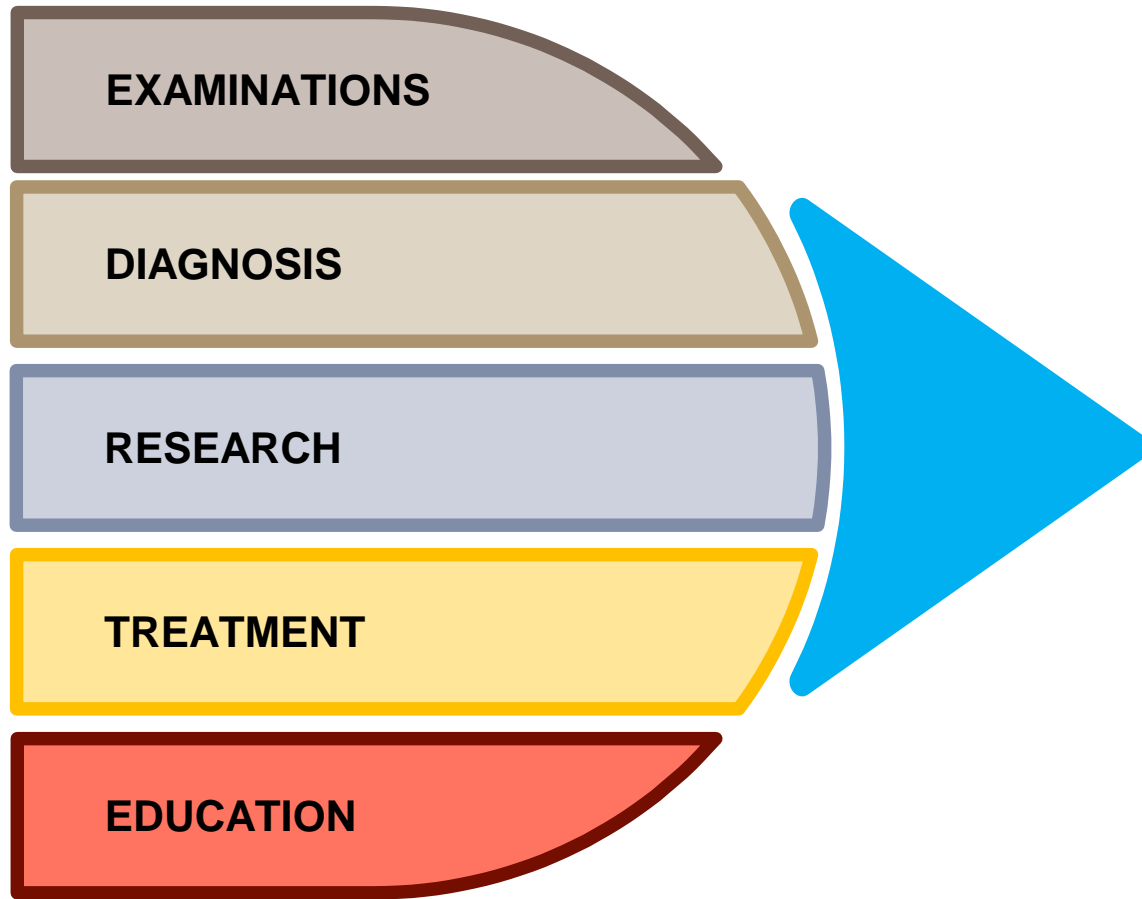
# INITIATIVES

Amongst all of the activities initiated or performed by the charity these are helping to reverse the situation –

- A Centre of Excellence - a UK/European hub for biomedical research into ME
- A strategy of high-quality biomedical research being sustained
- Clinical Trials for ME
- GP fellowship Scheme to educate doctors
- PhD students introduced to research to encourage interest
- Medical Students Involved in Research into ME to change the future
- European research collaboration with a European ME Research Group established
- A European ME Clinicians Group to build support and knowledge
- International Biomedical Research Colloquiums and Conferences
- International Young ME Researchers Network
- Advocacy and engagement in Europe



# WHY A CENTRE of EXCELLENCE



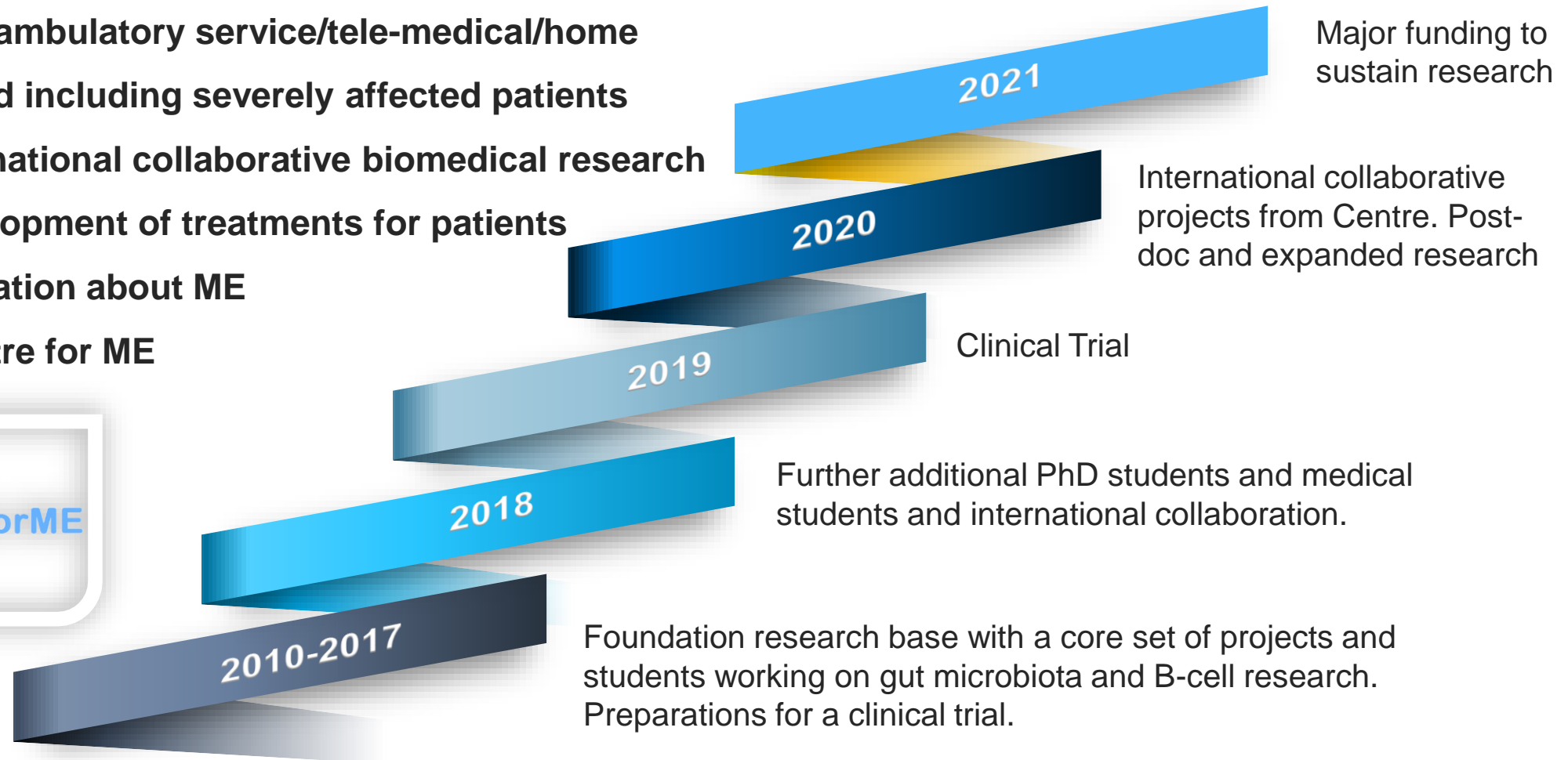
- Examinations by specialist consultants
- Housebound patients included
- Correct diagnosis using up-to-date guidelines and tests
- Translational Biomedical Research with clinical trials
- Focus on establishing cause of ME
- Develop Treatments
- Improve education about ME
- International collaboration



# A 5 year Plan for Research



- Sustainable development of research capability
- Development of ambulatory service/tele-medical/home visit services and including severely affected patients
- Expanding international collaborative biomedical research
- Expediting development of treatments for patients
- Up-to-date Education about ME
- Information Centre for ME

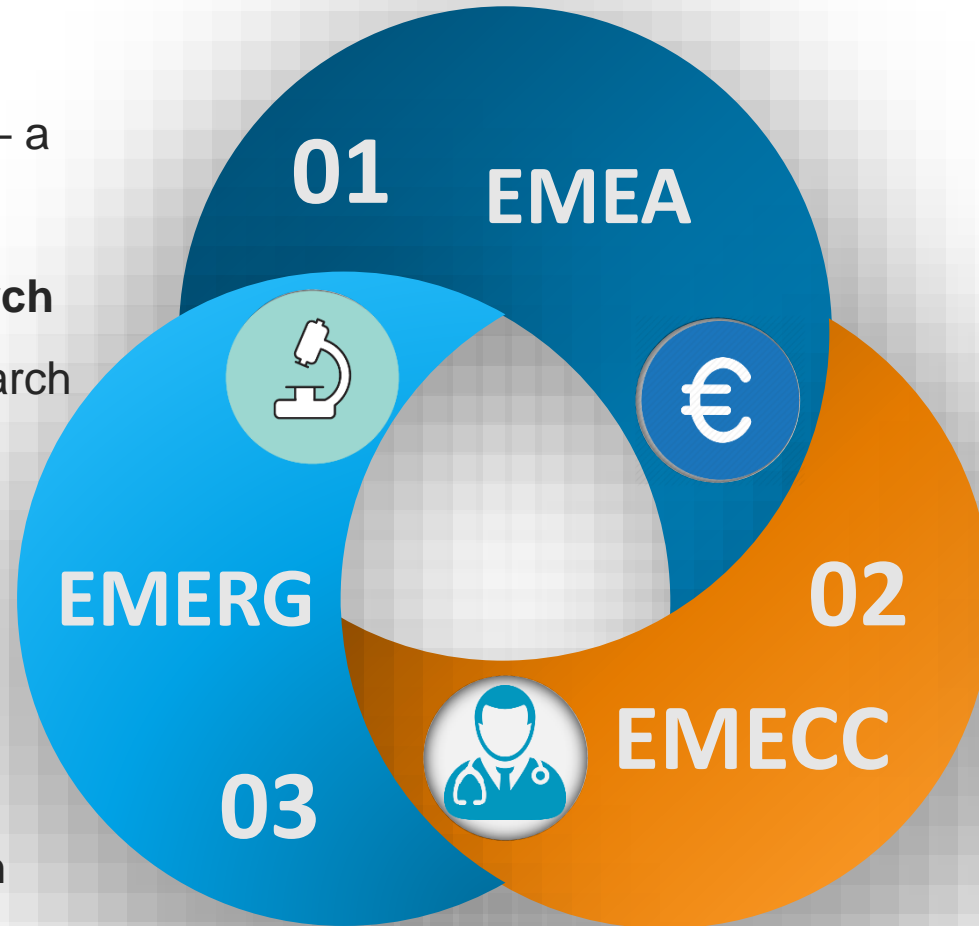


# European Collaboration



To facilitate international collaboration the charity has initiated formation of **European ME Alliance (EMEA)** – a group of patient organisations and charities, a **European ME Research Group (EMERG)** to develop research collaboration and a **European ME Clinicians Group (EMECC)** to build support and knowledge amongst clinicians.

The charity also arranges International Biomedical Research Colloquiums and Conferences, and an International Young ME Researchers Network.



**EMEA**  
Patient Organisations  
in Europe

**EMECC**  
A network of ME  
clinicians in Europe

**EMERG**  
A collaboration of  
researchers across  
Europe



“Vision without action is merely a dream.  
Action without vision just passes the time.  
**Vision with action can change the world.”**



**Our objective is to facilitate rapid progress**



# INVEST in ME RESEARCH

[www.investinme.org](http://www.investinme.org)

[www.investinme.org/2019Booklet](http://www.investinme.org/2019Booklet)

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