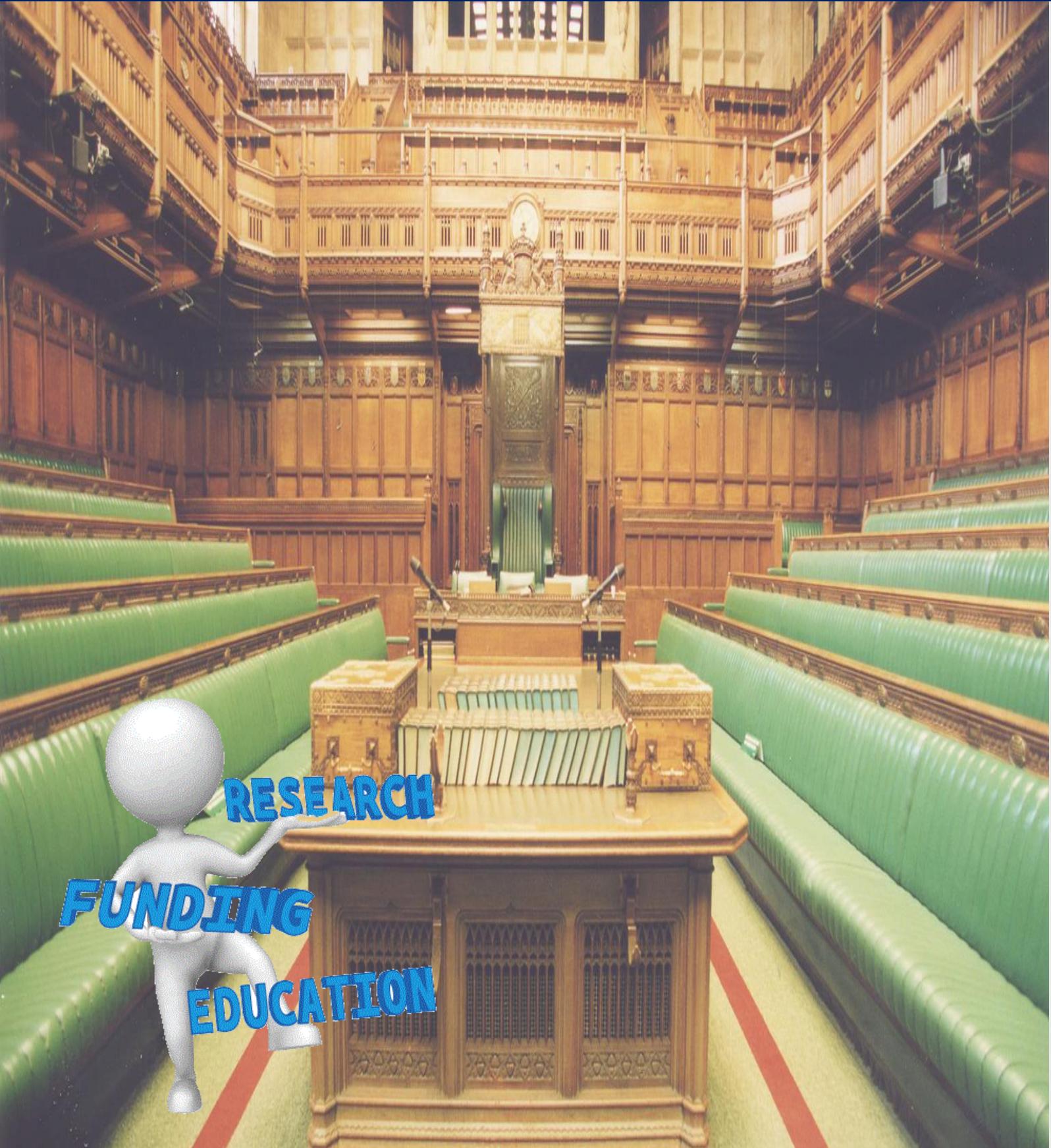




# *Invest in ME Research*

THE DEBATE IS OVER  
INACTION for ME IS NOT AN OPTION  
GIVE ME PATIENTS A FUTURE

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## 2 Introduction

In 1988 a parliamentary motion was brought by Mr. Jimmy Hood, MP for Clydesdale [1]. The request from this bill from 30 years ago –

“The Bill is a simple measure which merely requires the Secretary of State to make an annual report to Parliament describing the progress that has been made in investigating the causes, effects, incidence and treatment of ME.”

In 2002 the Chief Medical Officer (CMO)’s Report [2] made a number of recommendations to address the inequities regarding the treatment of people with ME.

In 2006 Dr Ian Gibson MP led an inquiry into ME [3], which made many sound, and rational recommendations to tackle ME.

- An annual report into progress with myalgic encephalomyelitis (ME, also referred to as ME/CFS)
- A report from the CMO recommending major changes.
- An inquiry from a leading parliamentarian, and chair of the science and technology select committee, making recommendations.

Logical, simple, coordinated.

Solutions that any health department or Chief Medical Officer or Secretary of State for Health might well see as common sense for a disease that affects so many and costs so much.

Now, 30 years after the 1988 debate, seventeen years after the CMO report, thirteen years after the Gibson Inquiry and none of the recommendations can be said to have been realised.

What more needs to be said?

The above parliamentary motion from 1988 and updated versions of the CMO Report and Gibson Inquiry recommendations could have been brought before parliament today - and (with some updates) would be welcomed by people with ME.

Such is the lack of any progress made.

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We summarised the issues and lack of progress in our status report on ME document [4] that provided an overview of the lack of action regarding research and treatment for myalgic encephalomyelitis (ME) in 2018.

That document was able to be used as a briefing document in the Westminster Hall debate of June 2018 and covers the problems in the way that ME is researched, perceived and treated.

All of the comments in this document are supported by that document.

A new debate on ME in the main hall in parliament has now been set for 24<sup>th</sup> January 2019.

The failure to address any of the issues with ME or take on board and implement the recommendations mentioned in the above initiatives illustrates that ME has been ignored for a generation.

It is the reason for the title of this document.

Debate is over.

Now it is time for action!

To quote Anne Örtengren **“You need to give ME/CFS patients a future.”** [5]

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### 3 Debate January 2019

Invest in ME Research welcomes this debate as it provides an opportunity to highlight some of the issues that the charity has been commenting on since it was formed, and allows recommendations to be received formally.

The subject of the debate is –

**“That this House calls on the Government  
to provide increased funding for biomedical research into the diagnosis  
and treatment of ME,  
supports the suspension of Graded Exercise Therapy and Cognitive  
Behaviour Therapy as means of treatment,  
supports updated training of GPs and medical professionals to ensure  
they are equipped with clear guidance on diagnosis of ME and  
appropriate management advice to reflect international consensus on  
best practice,  
and is concerned about the current trends of subjecting ME families to  
unjustified child protection procedures.”**

For this debate in January 2019 Invest in ME Research was not asked to contribute to preparations for the debate nor was it asked for input into the title or the subject of the debate.

Had we had the opportunity to do so then we would have advised differently.

However, in this document we comment on each of these points in the motion and follow with recommendations – with reference to the [Status of ME](#) document that we prepared for the June 2018 Westminster Hall debate [4].

We also summarise what needs to be done and what the charity has been doing to remedy some of these issues in the appendices.

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#### **4 Motion Point 1: To provide increased funding for biomedical research into the diagnosis and treatment of ME**

Note: What this point really ought to be asking is to provide appropriate funding for fundamental biomedical research into ME to enable determination

of the underlying cause(s) of the disease, the discovery of biomarkers for correct diagnosis and development of effective treatment(s) for the disease.

### Situation Today

- Funding for research into ME has been shown to be inadequate for the disease burden that exists for this disease [6, 7]. Very little research (by comparison with other diseases) has looked at ME. The tiny amount of funding that has been granted by public funding bodies has not even gone entirely to research into ME.
- The lack of adequate funding for any biomedical research from the public funding bodies has led to an imbalance in research that further aggravates the situation for people with ME. Government investment in research on ME has been given mainly to fund the so-called BioPsychoSocial (BPS) school of thought and next to none for biomedical research.
- No research has been funded by the Medical Research Council (MRC) to look at aetiology and pathogenesis of ME and successive governments always allow the MRC to escape responsibility in questions about types of research by giving the same vacuous response to requests with  
*“The MRC does not classify research in the area by type and is therefore not able to include a further breakdown by type of project.”*
- If fundamental biomedical research is not sufficiently funded then
  - it becomes almost impossible to discover biomarkers to enable correct diagnosis.
  - without correct diagnosis and adequately funded research it becomes difficult to develop effective treatments, let alone cure(s) for this disease.
- It also needs to be realised that it is not just funding that is an issue. A strategy is required for research. It means nothing to throw money at this issue without a strategy.
- Over the last decade many working groups and “expert” panels, and even a “collaborative” research group, have been set up by persons tasked with responsibility by the MRC, with the purported intention to resolve the research situation.

### **All of these groups/panels have totally failed to achieve anything**

Whilst failure has been an option for these panels and groups - one might even call it an objective after so many failed attempts - it is an abrogation and dereliction of responsibility that has had an untold effect on the lives of hundreds of thousands of patients.

It has, in fact, just led patients into believing something is happening when the reality is that these groups have had no intent to do much of anything – thus wasting years of patients' lives.

Providing research funding alone will not be the answer to diagnosing and treating ME patients properly.

Other issues need to be connected with lack of research funding, as there are direct consequences:-

- The lack of any strategy for finding treatments for ME has opened the door for quack therapies and businesses to be marketed – and even funded [6] – putting patients at risk.
- No standardised outcome measures have been defined for clinical and research purposes.
- Standardised guidelines for diagnosis have not consistently been used nor are they even demanded by the MRC. More researchers are using Canadian Criteria but this is all still largely been left to individual researchers.
- Nothing has been done to look at subgroups at all – no strategy exists.
- The lack of any official epidemiological study is a failure. This should have been an obvious choice for funding but even the CMOs of the UK have no idea of the prevalence of ME in the population, are therefore ignorant of scale of problem and are seemingly apathetic to overtures made by Invest in ME Research to determine this.
- The lack of funding for research produces an environment where clinicians are put off treating this disease properly. This disease needs consultants who are willing to specialise and be able to define valid cohorts of patients for research. How else can properly assessed patients be put forward for research?

### **What needs to be done?**

- The obvious decision that can be made to address the situation is to ensure that sufficient funding is available for biomedical research

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- Research is the key. A strategy of high-quality biomedical research can change the future and, by establishing results and providing more correct information, will take care of the ignorance that pervades the healthcare system and the media.
- However, it should not just be any research given the term “biomedical” which just satisfies one vested interest or group. Mere cosmetics of changing web sites and information material to use “biomedical” does nothing to fix the underlying issues.  
This requires funding for fundamental research within a strategy of research that maintains continuation in funding and support – not piecemeal offerings that often seem to be given to those who are on a “preferred” list of researchers and organisations.
- Indeed, we hope that any debate is not a pretext to fund predetermined institutes or consortiums favoured by those with influence in the public funding bodies. No one collaborative group deserves special treatment or favours.
- The decisions on applications and funding policies must be open, transparent, and not masked in dubious practices. Judging panels need to be objective and without pre-conceived views of the nature of ME. Awards must be fair and based on scientific merit not on a short-term policy created behind the scenes merely to pacify frustrated patients and dissipate further criticism.
- 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 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.  
Last year the government spontaneously doubled its contribution to brain cancer research following the death of one MP by pledging an extra £20 million on top of its existing commitment. It can surely do this to help up to 250,000 citizens suffering from ME and the millions of carers and family members affected by the consequences of the disease.

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- Diagnosis for a disease with no biomarkers depends on the medical professional's perception of the disease and requires as clear and accurate guidelines as possible to avoid mis- and missed diagnoses.
- Treatments can only be developed, tested and made available after correct research has been carried out – probably meaning clinical trials.
- Young people entering into biomedical research into ME need to be encouraged. This may follow new and adequate funding into the disease.
- The CMOs of the UK must also be charged with establishing the correct prevalence of ME in UK in order that the correct burden on society of these patients can be established. This may then focus minds on funding research to find the cause and developing treatments, if only for the financial savings gained. The current situation is absurd where nobody knows the true prevalence of this disease in UK.

### **What are we doing about it?**

- The aim of the charity is to make ME an illness which is properly understood and where adequate funding is provided for biomedical research into ME allowing treatment(s) and cure(s) to be found.
- Invest in ME Research has been arguing consistently since 2005 for a funded strategy of biomedical research into ME and it is clear that ME has been seriously underfunded by the public funding bodies due to influences which are not interested in biomedical research .
- 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.
- In the absence of adequate funding by public funding bodies Invest in ME Research and its supporters have been funding biomedical research – with patients and their families and charity supporters raising almost £900,000 for biomedical research

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- What is required is a model that has been described by Invest in ME Research since 2010 which involves concentrating research into a hub with translational biomedical research and appropriate examinations of patients, correct diagnosis, biomedical research and development of efficacious treatments [\[35\]](#)
- Since 2010 Invest in ME Research has initiated and developed this proposal for a Centre of Excellence for ME in Norwich Research Park (NRP).
- The facilities already exist in NRP for high-quality biomedical research and there is a willing and experienced team who can lead strategic, international and collaborative research.
- Indeed, international collaborations have already been established and continue.
- This outstanding facility - home to a major university, university hospital and renowned scientific institutes - can form the hub for UK and European biomedical research into ME and everything is already in place – bar the remaining funding to complete our five year plan.
- The charity already has funded several projects at the Centre [\[7\]](#).
- Quadram Institute in NRP already highlight ME as one of their targeted research areas [\[8\]](#).
- The foundations already exist to invest in biomedical research and we welcome support from other funding organisations to join us to support this development.
- We call on the government to support this.
- The charity has encouraged young people to enter into biomedical research into ME by funding several PhDs and working with institutes at the Centre of Excellence in NRP to encourage participation from early career researchers.
- The charity currently funds four PhDs with projects coming through.
- The charity has funded medical students to intercalate in their medical curriculum with biomedical ME research taking place at the Centre and has had a scheme to create these opportunities for some years. An example of

excellence produced by medical students who were funded by the charity illustrates how we can change things by educating new doctors [9].

- The charity has managed not just to initiate biomedical research but also to help influence new researchers and clinicians in the research park and in CCGs to become interested in ME research. NRP has the facilities and there now exists a willing and funded team who can lead strategic, international and collaborative research.
  - By investing in ME research in NRP the UK has a chance to form the major European hub for research into this disease that will attract resources, funding and, most importantly, will develop the strategy for biomedical research that will develop treatments for this disease. All of this has been made possible by the charity's vision in developing this concept.
  - The charity has arranged nine international ME research Colloquiums that facilitate and create international collaboration in biomedical research into ME. These research Colloquiums have spawned new ideas and created collaborations across countries.
  - The charity has also created a young/early career researcher conference to encourage new and young scientists to enter the field and support each other. The NIH are now working with us to establish this as a continuing international event and network.
- 

### 5 **Motion Point 2: ~~Suspension~~ Removal of Graded Exercise Therapy and Cognitive Behaviour Therapy as means of treatment**

Firstly, we must comment on the title in this request in the debate as it falls short of what is required.

CBT and GET must be **removed** (not suspended) as recommendations for treatment of ME.

On this point there is absolutely no compromise – nor should there be.

## Situation Today

- As we pointed out in our correspondence with Professor Mark Baker, Director of Guidelines at NICE [10] – CBT and GET have been shown to be harmful and need to be removed from existing guidelines.
- The USA Centers for Disease Control (CDC) updated their website about ME to use the 2015 Institute of Medicine report and removed Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) from its recommendations [11].
- The largest ever trial into these therapies (CBT and GET), the so called PACE Trial [12], proved that these therapies do not work for even loosely defined fatigue patients yet NICE still has these therapies listed in its guidelines for ME unlike the US health agencies that have removed them from their recommendations [13].
- The PACE Trial) has been proven to be flawed [14], possibly fraudulent [15] and a complete waste of taxpayers' money. Reanalysis of PACE Trial results by Matthees et al stated -
  - "This re-analysis demonstrates that the previously reported recovery rates were inflated by an average of four-fold." [16]
- The PACE Trial is now ridiculed as an example of how not to perform research – and it is widely seen as flawed. Several articles by David Tuller, academic coordinator of the concurrent masters degree program in public health and journalism at the University of California, have exposed these flaws and demonstrated that the PACE Trial cannot be considered valid [17]
- Testimony from patients shows that patients are often not believed. If they refuse to take CBT and GET then they are penalised by insurance companies [4], irrespective of whether that is legal or not. This has a knock-on effect in that patients become wary of engaging with a GP again – thus leaving the door open to the condition getting worse or other conditions being missed.
- Insurance companies refuse to pay disability premiums if the patient declines to undergo CBT and GET or is unable to.

## What needs to be done?

- We know very well that the government will respond that NICE are currently reviewing the guidelines and therefore must wait.

However, these reviewed guidelines will not be changed until 2020 at the earliest and there is no guarantee that NICE will remove CBT, or GET. Indeed, with the shambles of the current selection process for the guidelines development working group which has occurred then we have no faith in NICE delivering anything but a fudge with new guidelines, where patients' interests are again subjugated in favour of vested interests for the BPS lobby.

Meanwhile the existing guidelines still recommend CBT and GET and these can continue to do harm.

- CBT and GET must be removed (not suspended) as recommendations for ME to avoid more harm.

This must be done immediately – not wait for several years until a new incarnation of NICE guidelines is brought about, possibly recommending the same failed theories.

To do otherwise would be negligent. Negligence that has caused harm to people with ME must be met by accountability from those who ignore this harm and litigation may well be the consequence.

- NICE must also inform all healthcare providers around the world, who may be using the NICE guidelines for their own healthcare systems, that CBT and GET have been removed as recommended treatments.
- The NHS is currently wasting a huge amount of funds in peddling these failed therapies, CBT and GET, to ME patients which are either useless or deleterious to the health of ME patients. More importantly these therapies are rejected by patients and, at a time where the NHS needs all the funding it can get, there is no sense in wasting resources or funds like this.
- NICE must take full responsibility if CBT or GET do harm to patients whilst these remain as recommendations for treatments for ME by NICE.

NICE are responsible to the Department of Health so if the DoH (and the secretary of state for health) allow CBT and GET to be retained then they must also accept responsibility for the damage to health to patients.

## What are we doing about it?

- Invest in ME Research has consistently called for removal of both CBT and GET as recommendations for treatment for ME.
- Invest in ME Research has had extensive email discussions with Professor Mark Baker of NICE [10].
- These discussions clearly demonstrated that Professor Baker accepted that CBT and GET, as recommendations from the existing NICE guidelines, have done harm to people with ME.
- We have informed European health agencies.
- Along with our colleagues in the European ME Alliance we have advised healthcare agencies throughout Europe about the downgrading of CBT and GET by US agencies.
- Our submission to NICE for review reaffirmed these views.

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## 6 Motion Point 3: Supports updated training of GPs and medical professionals to ensure they are equipped with clear guidance on diagnosis of ME and appropriate management advice to reflect international consensus on best practice,

### Situation Today

- The NHS generally does not recognise or understand ME. For too long the misinformation about ME and the deleterious recommendations by NICE

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for CBT and GET have allowed a culture of ignorance to pervade the NHS regarding ME. This seriously affects the health of patients.

- As there is no clinical specialism responsible for ME then patients are being shunted to different areas of medicine in order to be treated or offered these quick fix therapies such as CBT and GET – both of which have been shown to be ineffective or harmful to people with ME.
- From the foreword of the CMO 2002 Report above -  
'...there are concerns from patients and their representatives, and from a broad range of clinicians, over the way the illness is managed. These concerns on management apply to the NHS, to other government Departments and to the private sector. In particular, patients and health professionals involved in the care of CFS/ME find much disbelief about the nature of the illness and of its impact. Perhaps as a result, in many areas of the country there appears to be a lack of appropriate health care facilities.'

Nothing has changed since 2002.

- We have stories of severely affected patients entering hospital and being sectioned or being made even worse.
- The NHS has been responsible for a constant use of misinformation about ME in their departments and on their websites and for a failure to keep up to date with current research on ME – as was amply demonstrated by the deplorable MUS Commissioning documents. [18]
- The level of knowledge within the NHS has been entirely influenced by the Biopsychosocial (BPS) [19] dogma from a lobby of psychiatrists who have vested interests relating to their having done consultancy work for insurance companies and DWP.
- The lack of adequate funding for any biomedical research from the public funding bodies has led to an imbalance in research that further aggravates the situation for people with ME.
- There is little point in asking for updated training of medical staff about ME if research is not adequately funded to provide an evidence base to underpin the education of medical professionals.

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All of these points are linked.

- To change this there needs to be a genuine will within the healthcare departments and decision makers to overhaul policies that rely on outdated views and information.
- In correspondence with the outgoing NHS National Medical Director, Professor Sir Bruce Keogh (correspondence that took three months to receive any reply) [20] Invest in ME Research received this response from Sir Bruce –

"The most recent NICE guidance advises that Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) are the most effective forms of treatment for ME/CFS."

The ignorant and superficial response is typical of career civil servants who occupy these positions of power. Had he discussed with NICE director Professor Mark Baker he would have been aware that everyone considered NICE guidelines to be unfit for purpose and CBT and GET harmful to ME patients.

- Sir Bruce's response illustrated to many a dysfunctional NHS management hierarchy that has no interest in tackling the issue of ME.
- No models of care have been developed or implemented.
- The education and training of doctors, nurses, and other healthcare professionals does not include ME.
- No facilities exist to handle the extreme sensitivities that people with severe ME experience if they need medical attention. A recent paper from Baraniuk et al illustrates the issues with ME patients presenting at A&E [21].
- The situation regarding care for ME patients is sparse and disparate standards are used.
- No up to date postgraduate education or training exists for ME. Medical school education regarding ME is often missing completely or limited to a page in a textbook that is out of date and even listed in the mental health category, despite the World Health Organisation and the UK

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government recognising the disease as a neurological illness under ICD-10 G93.3.

- Even NICE state that they can take a different view of ME compared to their supervisors – the Department of Health and do not have to follow WHO classification of ME [22].
- GPs and medical specialists are dependent on NICE guidelines.
- Patients are met with disbelief and even dismissal of their symptoms, and healthcare staff often consider ME to be non-existent. Much of this ignorance stems from NICE and DoH policies and the deleterious influences of BPS dogma.
- No acceptable courses exist for ME for doctors that are not based on these BPS theories of ME.
- Awareness and understanding of the illness among the public, and through schools, the media, employers, agencies, and government departments is very difficult when the media only listen to press releases from the biased Science Media Centre (SMC) and when organisations such as the CFS/ME Research collaborative (cmrc) have for five years included both SMC and proponents of the BPS theories about ME in their group.
- Awareness of the real story behind ME has been left to knowledgeable advocates and charities such as Invest in ME Research, whilst others avoid rocking the boat and remain silent on the major issues.
- The awareness of ME amongst the public and media has not increased due to any policies initiated by the CMO – there have been none. Awareness has only been increased due to the work of the many unsung heroes in the ME community who perform their work without any reward or without any self-promotion.
- We feel we cannot rate the education of healthcare staff or other sections of the community as having been performed well or even attempted to be performed.

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- The fact that a young woman can be sectioned in the twenty-first century in the UK, because she suffers from ME, means that education of healthcare professionals has not produced the desired result. [23]
- As if to underline all of the above Invest in ME Research met with the CMO in 2017 to discuss these issues. The CMO office showed little interest in medical education about ME, or prevalence of ME, or the consequences of ME and has done nothing to help people with ME. [24].

The CMO of England has not even responded to our simple request to pass a status message on to the 250,000 suspected people with ME in the UK [25].

- Invest in ME Research arranges an annual CPD-accredited international conference for professionals to hear of the latest research from around the world yet the CMO of England declines every single invitation to attend that is sent - and doctors remain under-educated about the disease. Ignorance and intransigence toward this disease stems right from the top.
- Thirteen CFS clinics were established by the government in the UK. Opinion on these varies - a couple were given credit by their patients (example in Norfolk or St. Helier and Epsom in Surrey) - due mainly to the lead clinicians believing in the organic nature of the illness. However, the job adverts for some of these centres a while back showed the clear bias towards behavioural therapies for ME which exists in the NHS. These clinics have also lacked appropriate services, nullifying the 2002 CMO Report recommendation – one even stating in 2012 “*As more is now known about chronic fatigue conditions...employing an immunologist directly is no longer necessary*”. [26]
- Clinics have closed or are being led by occupational therapists only and ME patients are increasingly being referred to the newly established/trialled IAPT (increasing access to psychological therapies) services which seem to be just another form of the failed biopsychosocial paradigm offering lifestyle management.
- Severely affected patients receive no specialist or domiciliary services.

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- The level of service is entirely inconsistent in the UK and does not appear to have been coordinated or funded properly.
- A few sporadic attempts by some charities/organisations and patients to engage with NHS and CCGs does not amount to a policy that has been created and enforced. Invest in ME Research spent four years sitting in meetings with NHS to address failures in healthcare provision for ME - wasted years that achieved nothing with no real intent by the NHS to change.

We are pleased to say that our Centre of Excellence for ME development is at last making CCGs more interested in research into this disease.

- Essentially the approach to ME has been shambolic at best and non-existent at worst.  
The NHS does next to nothing in respect of enabling self-management by the patient – other than to allow them to be removed from the healthcare system due to neglect.  
This is entirely due to DoH, NHS and NICE leadership ignoring the issues around ME – assisted by bias in the policies of public funding bodies.
- The best healthcare professionals will do whatever they can for people with ME (as for any other disease), they will listen to their patients and believe their illness, they will provide honest advice and remain up to date with current research.  
Sadly, these professionals are by far the exception when it comes to ME. Most healthcare professionals have little knowledge or understanding of ME and often have too little time to deal with this complex situation without the benefit of up to date knowledge of the disease.
- Patients visiting their GP with symptoms of ME face a lottery – where diagnosis may be ignored or mistaken, referral may or may not be provided, but with no certainty of any outcome.
- With no specialism taking responsibility for ME in the health service then no priority has been given to understanding the disease. This inevitably means that healthcare staff who feel they need extra skills have nowhere to go to seek and receive help in this area.
- General Practitioners would find it hard to manage moderate to severe cases of ME in the community setting without proper understanding and

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education about the disease. With no leadership from the UK CMOs or Royal Colleges then this often fails.

- Referrals to specialists, when they do occur, are to a variety of specialisms with little knowledge of the disease being applied to the choice of the specialism used.
- With NHS budgets being squeezed and healthcare staff being cut the future for provision of services for ME sufferers is not itself healthy.
- Whilst it is felt that progress is gradually taking place in the perception of ME by clinicians it is still too sporadic and is only being achieved due to the work of organisations such as UK charity Invest in ME Research.
- Healthcare professionals may be learning more about ME but they are still heavily influenced, and therefore biased, by the indoctrination from flawed NICE guidelines and lack of funding for biomedical research.
- Patients deserve honest advice and unbiased research leading to discovery of the aetiology of the disease and development of treatments.
- Yet recognition, assessment, management and support of people with ME does not regularly, or even often, occur.
- Where do healthcare workers who feel they lack the skills go to for more experience? Nothing has been done to support them.
- The problem exists whereby patients may receive a diagnosis, and may even see a referral to some specialist decided by a GP. However, often patients are then left with no care as there are no treatments available and patients are then removed from the healthcare system. These patients may then manage the situation themselves for decades with no access to any healthcare and the possible of comorbid conditions being missed or ignored.
- There is no evidence to suggest that management of the illness has been extended to cater for carers and family members and nothing to suggest this has even been considered. Carers are also left in a vacuum - absent of attention.

- Doctors refer to NICE guidelines for ME as they are afraid of being victimised if they try something different (27). Yet the guidelines programme director has himself stated that NICE guidelines for ME (the “best national guidance”) are unfit for purpose and will be “torn up”.

### **What needs to be done?**

- We are sure that the government will merely respond that NICE are responsible for guidance and they are undertaking a review of the current guidelines that have been so heavily criticised and that this will report in 2020.

However, if NICE fail then who takes responsibility and who corrects the situation?

NICE has failed – something even admitted by the Director of Guidelines development at NICE

- A specialist consultant needs to be trained for ME  
There is also a need for academic consultants who can assist in developing the research and clinical care and education.
- Medical curricula need to be revised.  
All medical schools need to ensure that their curricula are brought up to date to recognise ME as a disease.
- The conflicts of interests underlying the current misinformation need to be addressed and investigated before a fresh start can be made
- Diagnosis for a disease with no biomarkers depends on medical professional’s perception of the disease and requires clear descriptive guidelines to avoid mis- and missed diagnoses.
- Guidelines must be up to date and the Canadian Consensus Criteria are increasingly used by researchers and clinicians.
- NICE guidelines have proven to be without value.

### **What are we doing about it?**

- liMER wrote to the GMC in 2010 believing them to be responsible for medical curriculum for students and asking why they do not act on this dangerous inconsistency [28] but little attention seems to be paid to this subject.

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- Invest in ME Research are UK distributors for the Canadian Consensus Criteria (CCC) [29] known as the Canadian guidelines which are being used by more and more researchers and many clinicians to diagnose ME. The charity has supplied this document to numerous GP surgeries and healthcare professionals as well as sourcing it for other charities and organisations to distribute – along with the ICC [29].
- Invest in ME Research provide an annual CPD-accredited international conference for professionals to hear of the latest research from around the world and this brings together clinicians, researchers and patients and carers to facilitate knowledge sharing and awareness - yet even the CMO declines every single invitation to attend that is sent to her and doctors remain under-educated about the disease.
- Invest in ME Research has purposely funded the inclusion of medical students in the biomedical research being funded by the charity [31] to enable them to meet patients, learn more about ME and augment the meagre education that their medical curriculum provides them. The response from medical students has been encouraging and this will help create a safer environment for patients in the future.
- Invest in ME Research is funding and encouraging young and early career researchers to enter the research field. We have arranged an international conference to bring these young researchers together and create a network to share knowledge. This is open to medical students also.
- Invest in ME Research has sent GP packs to GP surgeries in Scotland and to many around the UK.
- The charity has now arranged 14 annual CPD-accredited international conferences in London for healthcare professionals and patients and the public. These allow the latest research from around the world to be platformed.
- The charity's latest initiative is to establish a European ME Clinicians Council – a group of leading clinicians in Europe who will collaborate in forming standards for diagnosis and treatment for ME and support each other with their experiences, and be a focal point for correct clinical

information on ME. This group will be able to advise healthcare departments and the media about ME.

- Aside from the international conferences Invest in ME Research has now organised nine international research Colloquiums that has been responsible for bringing together researchers from all over the world to work together and form collaborative ventures.
- The charity also organised the European ME Research group (EMERG) concept to form a group of European researchers who would work together. This has already led to some collaborations and further ongoing work is planned.
- Our Centre of Excellence for ME model was designed to encourage collaboration between researchers and clinicians and enable better understanding of the disease.

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## **7 Motion Point 4: Concerned about the current trends of subjecting ME families to unjustified child protection procedures**

### **Situation Today**

The subject title of this point in the debate does not call for action but expresses concern over current trends.

This is actually quite incorrect. It requires more than “concern”.

This is NOT a “current trend” either – it is a fact that has heavily influenced the lives of patients and families for a generation.

Invest in ME Research does not express concern over families being subjected to unjustified intrusion into their lives by child protection offices – we demand action to change this.

- The charity has been involved in such cases and has had communication with families who have had to worry themselves sick over the draconian and totally inappropriate actions by social services who are very often

completely ignorant of the disease and its effects. Whilst having to protect their family from the ignorance of the state machine parents are still trying to take care of their child/children who are suffering from ME.

- The ignorance about the disease that has often been present in social services is also not an isolated incident in how ME is treated. It is directly related to the biopsychosocial (BPS) domination of research funding and the media. It is only because large funding has been given to these BPS research projects that debases and corrupts the whole environment, leaving social workers with no education about the disease and little encouragement to understand it.
- Children are very vulnerable to intervention from social services due to this ignorance and by incorrect advice being directed from some paediatricians who also follow the BPS dogma.

This may impact families who are accused of Fabricated or Induced Illness (FII) just because they are concerned for their child. Or children may be accused of modern-day superficial and ridiculous constructs such as Pervasive Refusal Syndrome. An insidious situation that, in our view, is not helped by some comments from establishment figures who help maintain this situation - such as “Combining graded exercise therapy and cognitive behavioural therapy has undoubted benefit.” and “..referred to Professor Crawley’s FITNET trial as “high quality research” [32, 33 ].

- It is also directly linked to the lack of a specialism being created for this disease in healthcare, where no consultants are trained and little education is given to medical students in the curriculum. All of this helps create an environment where the idea that people can recover if they just think the right way and exercise their way out of it is maintained.

### **What needs to be done?**

- A specialism in ME paediatrics would give more authority to those who treat patients. It would allow better and more up-to-date education on the disease linked to research findings. This would allow social services to receive expert help.
- Education needs to extend to social care. Courses must be adapted to include real and up to date knowledge concerning ME.

- Visits to clinicians who are knowledgeable about ME should be arranged. Doctors who specialise in this disease need to be able to instruct social services
- Schools need to be educated about ME. Too little knowledge exists in schools about the disease and this ignorance can have drastic effects on families, which can be exacerbated by the ignorance and heavy-handedness of social services.

### **What are we doing about it?**

- Invest in ME Research organised a conference call in 2013 with Dr Martin McShane, Director of Domain Two, NHS Commissioning Board  
We held this meeting with a family who had been subject to the unjustified attention of child protection services due to the ignorance about the disease in the NHS and elsewhere. [\[30\]](#)

In that meeting the parents of the very severely ill young person gave a presentation of their experiences since their child became severely ill at the age of 8 in 2000.

The presentation was very powerful and was conveyed in a very professional manner despite the obvious anguish and distress that it caused the parents.

The picture painted was awful –

- where GPs took no responsibility for a cluster of people who became ill at the same time in the small village;
- where severe ME caused panic in healthcare professionals who wanted quick fixes and looked around for some other causes in parents or patients (Munchausen's by Proxy, Pervasive Refusal Syndrome and so on ) despite the UK government and CMO Report recognising ME as an organic illness;
- where good doctors who had kept children safe from the threat of child protection orders were retired and parents had nowhere to turn to for support;
- where OTs were helpful but GPs had been terrible;
- where GPs, consultants and paediatricians all facilitated removal of parental support stating that ME is not a real disease;
- where GP visits were unannounced and the family was reported to social services for neglect and were then asked to leave the GP service;

- where complaints were sent to PALS but where doctors had refused to comment.

This representation was enough to convey what many in the UK had felt for a generation and for which little has, or is being done.

Dr McShane commented that to change the quality of life with long term conditions we have to accept what we do not know.

liMER felt this was not good enough.

- It would be a straightforward task to produce guidance for social workers based on correct information about ME.
  - To remove isolation from young people with ME and maintain contact with schools Invest in ME Research looked to the latest technology and engaged with a Norwegian company to initiate a trial of classroom robots for those children who were absent from school due to the illness [34].
  - The newly created European ME Clinicians Council could assist in educating social services [36]
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## 8 Recommendations

In our report of the status of ME from 2018 [4] the charity made a number of recommendations. These are listed and we add those mentioned in this document.

### 1 A Public Inquiry into ME

There needs to be a full and independent public inquiry into the handling of policies toward research and treatment of ME since the CMO report of 2002. It is not enough for public funding bodies and establishment departments to respond to this debate and imagine that everything continues with small tweaks to funding. It is difficult to trust any future policies of some of these agencies and offices if the same issues that have caused harm to people with ME are not addressed fully.

A new beginning must be made. In order to do that, and to avoid the same manipulation of patients' lives from continuing, we call for a comprehensive review of the way that ME has been researched, funded and treated by

establishment organisations. These include the Department of Health, Chief Medical Officer, Medical Research Council, National Institute of Health Research, Royal Colleges and other departments that seem to have influence over the lives of people with ME, such as the Department of Work and Pensions. This public inquiry would examine the behaviour and policies of these institutes and officials and departments and ministers and other agencies and organisations dealing with ME since the CMO report of 2002.

A public inquiry is justified.

### **2 Implement the Revised CMO Report Recommendations**

The recommendations from the CMO Report of 2002 should 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 more responsibly in promoting awareness and research and treatment of this disease.

### **3 Removal of Existing NICE Guidelines for ME immediately**

This has been stated above and in extensive correspondence discussions with Professor Mark Baker of NICE [[10](#)].

These discussions clearly demonstrate that Professor Baker accepts that CBT and GET, as recommendations from the existing NICE guidelines, have done harm to people with ME. We therefore feel that the existing NICE guidelines for ME must be withdrawn in order that more harm is not done to people with ME.

To do otherwise would be negligent.

NICE must also inform all healthcare providers around the world, who may be using the NICE guidelines for their own healthcare systems, that this addendum has been made.

### **4 Annual Report to Parliament of the Status of ME**

An annual update to parliament from the Secretary of State for Health to provide a simple measure that merely requires the Secretary of State to make an annual report to Parliament describing the progress that has been made in investigating the causes, effects, incidence and treatment of ME.

This proposal was good thirty years ago – it is good today.

The CMOs of UK must be directed to input into this report and provide accurate figures for numbers of people with ME, how many are being actively

treated or managed, and what is the average period for diagnosis a patient with ME.

### 5 Transparency of Meetings Concerning ME by MRC

Full transparency of any meetings between NIHR, MRC, DoH, NHS, Chief Medical Officers, Chief Scientific Officers and any charities or organisations purporting to represent people with ME or purporting to be interested in research into ME must be shown.

### 6 Removal of Those Previously Responsible for ME from Positions of Influence

It would seem sensible to request that those individuals who have been connected with MRC decisions on research into ME over the last decade must, if still in positions of influence with regard to ME research, be removed from having any influence on future decisions regarding ME.

The people whom the MRC has made responsible for ME have failed and should play no further role in influencing any policies relating to ME.

Those who have conflicts of interest within the MRC, NIHR, DoH and who have any influence on ME research need to declare those interests.

We also call for the Principal Investigators of the PACE Trial to be barred from receiving any further public funding for future research into ME due to the flaws in that trial.

### 7 Research Funding

Dedicated funding for biomedical research into ME should be provided. We have already proposed that **£20 million** per year for five years would kick-start this research and offer real hope to address some of the above-mentioned issues.

A strategy of high-quality biomedical research must be created.

The decisions on applications and funding policies must be open, transparent and objective and based on scientific merit.

Young people entering into biomedical research into ME need to be encouraged. Conferences such as those arranged by Invest in ME Research will help but funding of research needs to be given to make it worthwhile for young people to make their career in ME research.

**8 Guidelines for diagnosis must be as accurate as possible and must be up to date.**

**9 The CMOs of UK Must Annually Report on Prevalence of ME in UK**

The CMOs of the UK must be charged with establishing the correct prevalence of ME in UK in order that the correct burden on society of these patients can be established. This may then focus minds on funding research to find the cause and developing treatments, if only for the financial savings gained.

The current situation is absurd where nobody knows the true prevalence of this disease in UK. Without this knowledge, the burden from this disease on society cannot be accurately determined.

**10 Patients Diagnosed with ME Need a Regular Follow-up pathway**

It seems a common occurrence that patients who have no access to treatments for ME are often lost from the healthcare system. This can create a situation where comorbidities develop and are ignored or unknown. Patients who have had the disease for decades must have access to a thorough examination as a rule rather than an exception.

If necessary, due to the severity of a patient's condition, then this should be made available as a home visit.

**11 NICE Must Follow Department of Health View of ME**

**12 A specialism consultant needs to be established for ME**

There is also a need for academic consultants who can assist in developing the research and clinical care and education.

**13 Medical curricula need to be revised.**

All medical schools need to ensure that their curricula are brought up to date to recognise ME as a disease.

**14 Education needs to extend to social care.**

Courses must be adapted to include real and up to date knowledge concerning ME. Visits to Clinicians who are knowledgeable about ME should be arranged. Doctors who specialise in this disease need to be able to instruct social services

## 15 Schools need to be educated about ME.

Too little knowledge exists in schools about the disease and this ignorance can have drastic effects on families, which can be exacerbated by the ignorance and heavy-handedness of social services.

## 9 Final Comment

Finally, comment from the charity to the government and to those who might view this prior to, during or after the parliamentary debate.

In all of the time that Invest in ME Research has been active it is apparent that this disease has not been treated fairly or adequately by the healthcare system or by the establishment organisations responsible for influencing research and medical knowledge relating to this disease.

People are suffering daily from this disease – and not just patients, but their carers, their families and their friends -

- from the young child who has been recently diagnosed and who may be looking forward to a future with reducing social contact, more severity of symptoms and exclusion from society;
- to the severely affected patient who has no treatment and often no access to healthcare and whose daily torment and suffering is witnessed only by an exhausted, unpaid carer – usually a relative;
- to the patient who has had to bear the consequences of this disease for decades, always trying to remain optimistic yet increasingly falling to the effects of possible comorbidities which that remain undiagnosed and untreated.
- to the carers – fathers, mothers, wives, husbands, children, friends - who have the odds stacked against them if the person(s) they are caring for suffer from ME, and have to stop their normal life to try to come to grips with the effects of this disease on themselves as well as the patient they are caring for.
- and worst of all to those who have no carers or family members to look after them and advocate for them

It is difficult to convey fully the overwhelming effects of severe ME to anyone who has not experienced them – on the patient or on carers. We can only allude to the horrendous course that ME can take, point out at how little has

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been done to address this particular issue of ME, and state what we, as a charity, are trying to do to change things.

This disease affects young children, it affects older people, it can severely affect patients who receive no care and suffer indescribable pain, it affects patients for many years and there are many who have lived for several decades with this disease – a fact rarely recognised.

**This disease destroys lives and it needs to be addressed once and for all.**

The one thing that should be realised from this debate is how urgent this situation is.

People in this country cannot continue to be treated as an after-thought, as a statistic, as a section of the population who are discriminated against.

It will take more than a parliamentary debate, and it will take more than a one-time offer to fund any one chosen consortium or group of favoured researchers.

It requires a long-term strategy and regular monitoring and it requires accountability of those charged with addressing this issue.

Read some of the final words from Anne Örtegren [\[5\]](#) who tragically had her life taken by this disease -

“If you are a decision maker, here is what you urgently need to do:

You need to bring funding for biomedical ME research up so it’s on par with comparable diseases.

You need to make sure there are dedicated hospital care units for ME/CFS inpatients in every city around the world.

You need to establish specialist biomedical care available to all ME patients; it should be as natural as RA patients having access to a rheumatologist or cancer patients to an oncologist.

You need to give ME patients a future.”

## 10 Appendix 1 References

Ref	Reference Link
1	<a href="#">Parliamentary 1988 a parliamentary motion</a>
2	<a href="#">CMO Report 2002</a>
3	<a href="#">The Gibson Inquiry</a>
4	<a href="#">Status of Research, Treatment and Perception of Myalgic Encephalomyelitis 2018</a>
5	<a href="#">Anne Örtegren - A Year On</a>
6	<a href="#">Chronic Fatigue Syndrome:Written question - 146298</a>
7	<a href="#">ME - Science Friction in the UK</a>
6	<a href="#">The SMILE Trial</a>
7	<a href="#">Projects Funded by Invest in ME Research</a>
8	<a href="#">Quadram Institute - A coordinated, collaborative approach is vital to understanding the origins of this complex, debilitating condition</a>
9	<a href="#">A Role for the Intestinal Microbiota and Virome in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)?</a>
10	<a href="#">Correspondence between liMER and Professor Mark Baker of NICE</a>
11	<a href="#">The CDC Updates their website about ME/CFS</a>
12	<a href="#">The PACE Trial Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. Lancet 377: 823–836. doi: 10.1016/s0140-6736(11)60096-2</a>
13	<a href="#">USA Agency for Healthcare Research and Quality (AHRQ)</a>
14	<a href="#">A preliminary analysis of 'recovery' from chronic fatigue syndrome in the PACE trial using individual participant data</a>
15	<a href="#">Kelvin Hopkins Questions in Parliament on the PACE Trial</a>
16	<a href="#">Reanalysis of PACE Trial results by Matthees et al</a>
17	<a href="#">David Tuller articles on PACE Trial</a>
18	<a href="#">MUS Commissioning Document</a>
19	<a href="#">Invest in ME Research - Flaws in BPS Theory for ME</a>
20	<a href="#">Correspondence between liMER and Bruce Keogh NHS</a>
21	<a href="#">Chronic fatigue syndrome in the emergency department</a>
22	<a href="#">Developing NICE guidelines: the manual</a>
23	<a href="#">Sophia Mirza</a>
24	<a href="#">Invest in ME Research Meeting with Chief Medical Officer</a>
25	<a href="#">One Simple Question</a>
26	<a href="#">Leeds clinic</a>
27	<a href="#">The General Medical Council - Dr Nigel Speight</a>
28	<a href="#">GMC education</a>
29	<a href="#">CCC and ICC Guidelines</a>
30	<a href="#">Meeting with Dr Martin McShane</a>
31	<a href="#">Medical students in Research into ME</a>
32	<a href="#">Chronic Fatigue Syndrome: 'Surrounded by uncertainty'</a>
33	<a href="#">Formal complaint from Countess of Mar to BBC Director General about FITNET story</a>
34	<a href="#">Removing Isolation from Young People with ME</a>
35	<a href="#">Invest in ME Research - A UK Centre of Excellence for ME</a>
36	<a href="#">European ME Clinicians Council</a>