Journal of IiMER

#InvestinMEresearch

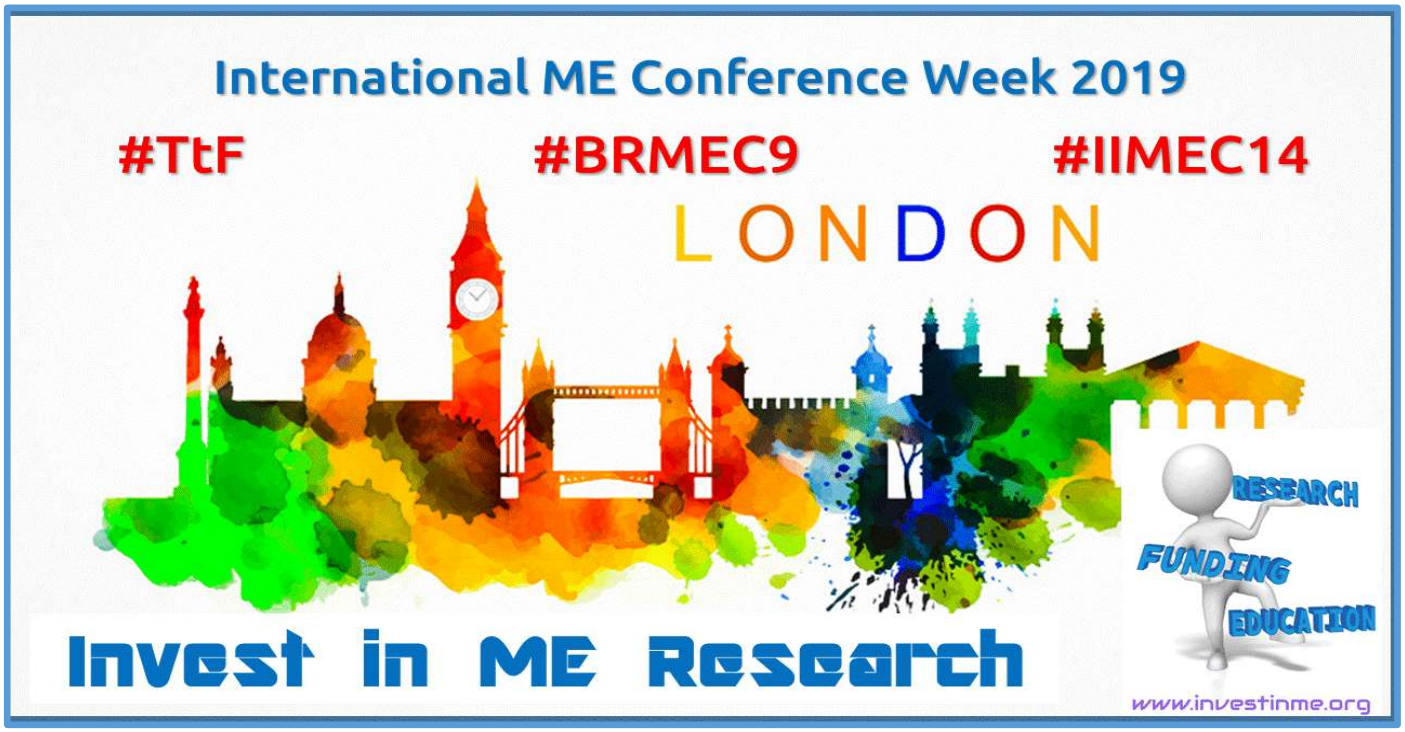
from UK Charity Invest in ME Research

Volume 13 Issue 1

We are trying to grow our research fund for biomedical research into ME. Green fingers anyone?

Help us establish a Centre of Excellence for ME hub Europe and enable a strategy of high-quality biomedical research, coordinated and collaborating with other institutes
http://www.investinme.org/fund

Invest in ME Research (UK charity nr. 1153730)
www.investinme.org email: info@investinme.org



In this Issue

FOURTEEN YEARS

Invest in ME Research is an independent UK charity facilitating and funding a strategy of high-quality biomedical research into Myalgic Encephalomyelitis (ME or ME/CFS) and promoting better education about ME.
The charity is run by volunteers - patients or parents of children with ME - no salaries, no government funding, but wonderful supporters.

This is the fourteenth annual international ME conference that this small UK charity has organised - a fact which surprises us on many levels.

It is a surprise that we have managed to continue to arrange these conferences, and even increased their scope - despite comparatively few resources.
A surprise that there really has not been the progress in research that we believed would and should have come after all these years.
A surprise that it has taken so long before any major national agency has taken this disease seriously.
A surprise that many other national research councils, especially in UK, are lagging so far behind and have ignored this disease for so long.

Yet where would we be now had it not been for the dedication and efforts of our supporters throughout these years who have made it possible for us to redirect research toward biomedical and influence and force a new direction for ME?

These are not just mere words for us - not a fresh update to leaflets, not a soundbite to pacify ME patients in order to retain support, not a new tactic to attempt to maintain the status quo, not another strategy to do deals behind closed doors and maintain establishment influence on progress.
During all these years the charity has consistently and unambiguously campaigned for dedicated biomedical research into ME and the necessary funding to achieve it.
We believed progress would be more rapid and it is sad that the opportunities that we presented and the offers that we made to engage were not taken up by establishment organisations as so much more might have been achieved in tackling this disease at that early stage, rather than waste lives by doing so little.
Yet without the efforts of our supporters throughout these years the scene could have been quite different and far worse.

We named the Colloquiums the "Biomedical Research into ME Colloquiums" as we wanted to make the point that we would not compromise.
Biomedical research was the way forward to make progress.

The conferences were designed for professionals in order to increase the education of healthcare staff and influence the future treatment of people with ME. However, we have always ensured that the conferences were also open to patients and carers, believing that having patients, carers, researchers, doctors, nurses and even the media interacting with each other was a good thing.

The charity has facilitated the foundation for a sustainable strategy of biomedical research into this disease. Our plans for a Centre of Excellence for ME have captured the imagination and is clearly seen as the way ahead - and good progress on this has been made, although with more resources the charity could expedite this for the benefit of all patients.
The Centre of Excellence for ME project began in 2010 and the charity was able to fund the first PhD studentship some years later.
This approach to research offers the best way forward for ensuring biomedical research into ME can be maintained and treatments developed.

Collaboration has been at the heart of the charity's innovation following a review after the 2007 conference and our strategy of bringing the best researchers from around the world together was formed. The acceptance of this vision and collaborative strategy has matured to the point where now the NIH is taking a lead in forming centres and collaborative strategies.

Collaboration and working together have been themes for our Colloquiums - with real international cooperation forming which can only lead to a better future for patients than would otherwise be the case. To support this strategy the charity has

continued to arrange the international ME conferences that have provided a platform for education about ME - with DVDs produced of all the conference presentations which have formed a historical record as well as providing knowledge of the latest research.
The Colloquiums and Conferences have always had an international atmosphere – emphasising that international collaboration in research and treatment are necessary.

Our original conferences have now developed into a unique conference week in the heart of London with delegates and colleagues and friends coming from over twenty countries around the world.

ME Conference Week 2019 now includes a conference for young/early career researchers; a dinner where young researchers can meet more experienced scientists; a two day closed research Colloquium where researchers can share ideas and discuss and plan and collaborate; a researchers' dinner where more discussions can be had; a pre-conference dinner which allows a special gathering of researchers, clinicians, media folk, politicians, ME patient group representatives,carers and patients to interact; a public international conference; a post-conference dinner which allows researchers and patient groups to discuss further after the main events have finished and plan the next steps; and an annual general meeting for the European collaborative patient alliance.
A small charity with wonderful supporters has achieved this.

When people view charities as being "the largest" or "the main" organisations it is as well first to determine how those adjectives are measured. Is it by income, by number of staff, by the amount of media presence? Or by the amount of income spent on research, or on the least spent on admin and salaries, or on the achievements and ideas that actually are realised?

It is achievements that count - always - and hopefully the ideas that actually are realised, where possible.
The supporters of the charity may not get the publicity they deserve but actions speak far louder than words, or awards.
In the recent parliamentary debate on ME, Invest in ME Research produced a document which summarised the status of ME. It also laid out a bold vision for research – including proposing that £20 million be allocated every year for five years to kick-start biomedical research and support the foundations that have been laid.
It is this vision that a small charity and dedicated supporters brings to the world of ME.
We were happy to contribute to the parliamentary debate that originated from the early work performed by a supporter of Invest in ME Research who is a constituent of the SNP MP Carol Monaghan, who set up the debate.
Being an independent charity allows a genuine approach to tackling the problems with ME that benefits patients and their families.

As Dr Ian Gibson - our conference chair for all these years - has said "We can change things"

As we host our largest ever “invite-only” closed research Colloquium (with more than 130 invitations being sent out) then the name of our charity truly becomes the main calling for all interested in resolving this disease.
For our fourteenth conference, and our ninth international researchers' Colloquium, what better slogan to use at this point in time than the one that this small charity has uniquely been promoting for so long.
Time to **#InvestinMEresearch**

Kathleen McCall

CHAIRMAN INVEST IN ME RESEARCH

We would like to thank our friends from the **Irish ME Trust**, **Norges ME Forening** and the **Open Medicine Foundation** for donating to help fund the administration costs of the conference.

Jonas Blomberg

Over the years, whilst the charity has been making huge efforts to encourage and facilitate international collaboration in research into ME, we have come into contact with hundreds of researchers in different research fields, in different institutes and in different countries.

There are many researchers whom we have known who have become trusted friends.

One of those researchers whom we have called a friend of the charity and a friend of people with ME was Jonas Blomberg.

One liked Jonas instinctively from the beginning. He was the type of person who would always give an unbiased and objective view on science - with no pretensions or separate agenda.

Jonas was the epitome of a researcher with integrity, honesty, approachability and scientific skills. Jonas came to one of our early international conferences after being encouraged by a member of RME Sverige.

Following that meeting we invited Jonas to every conference as our guest. He was also invited to our first Colloquium and attended every one of these events since that time. His was one of the first names that we entered when planning these events ten months before.

Such was the level of trust and friendship that we asked Jonas to be a chair for many Colloquium sessions and sum up conclusions from the Colloquiums.

Integrity – always.

Jonas was scheduled to chair, once again, the Thinking the Future – Young/ECR Conference in London in May – having successfully chaired last year’s inaugural event. Jonas would also have been attending and chairing this year's 'Conference and Colloquium and Thinking the Future events.

The news of his sudden death comes as a major shock to all at the charity.

This affects all of us and is a great loss to ME.

Our memories of Jonas are of the best - and he will be greatly missed by all.

Fifty Years - and ME?

In medicine, healthcare, technology and science the last fifty years have seen some dramatic developments that are nowadays taken for granted.
Antibiotics dramatically reduced death rates due to infection and today even new classes of antibiotics are being produced – even synthesised versions – to tackle superbugs
Organ transplants have become commonplace - with thousands of transplants being performed every year. Artificial organs have been developed.
Anti-viral therapy for HIV has transformed the prospects of patients from a fatal to a managed condition.
Vaccinations developed against many infectious diseases have changed society.
Imaging technology such as CT, MRI, and PET has revolutionised the detection of disease.
Anti-TB therapy practically eradicated tuberculosis, until recently.
Major advances in knowledge of the genetic code has laid foundations for the -omics branches of science.
Kidney dialysis, endoscopy and laparoscopic surgery, inhaled therapy, cataract treatment, statins, beta-blockers...etc.

Revolutionary developments now in everyday use, improving lives of patients.

Technologies too have changed the world
Computing power and development has turned the future into the present with technologies such as artificial intelligence.
With the rapid pace of development in science and technology then this overflows into medicine.
Unbelievable changes are being developed and tested - such as 3D printed body parts, new complex and even remote surgical procedures , gene therapy , gut bacteria treatments, cancer immunotherapy, synthetic cells, reprogrammed cells , mitochondrial replacement therapy .....it goes on and on.

If one can dream one can think the future. It all seems possible.

And myalgic encephalomyelitis?

Well, all of the above have had great effects on society and even people with ME will have benefited from some of these developments.
However, what of ME itself?

Fifty years ago, we celebrated the anniversary of the first moon landing.
The amazing photograph showed earth as seen from the moon for the first time.
How amazing, even today, to see this image and imagine that this could be achieved with computing power less than is now available in a mobile phone, and with technology that seems ancient by today's norms.
Yet who would have thought that fifty years would go by and people with ME would still have no specialist services, no treatments, no funding for fundamental biomedical research?

For ME we are still discussing the criteria, the name, the politics.
We are still frustrated that there is no adequate research funding.

We still suffer – at least since the beginning of this decade – of the evil that is the biopsychosocial (BPS) doctrine.

We should have made far more progress than has been the case in fifty years.

Yet ME has failed to achieve the progress that other areas of medicine and science have enjoyed.

ME has been forced into a retarded development due to the malign forces that have kept a few in positions of influence and power in order to support policies that have long been known to be damaging.
Patients have been played.
And who benefits from this continued stalling of progress?

Progress with ME may well depend on some of the above mentioned developments in science, technology and medicine.

The view regarding ME fifty years had seemed to be, until recent years, as bleak as the moon must have appeared to the crew of Apollo 8.

Yet we can hope that even the most entrenched of establishment policies will finally be swept away.

Fifty years ago we were amazed to see our world from another celestial body in all its splendour.

Another fifty years cannot pass without seeing solutions to ME being realised.

Status of ME 2018 - www.investinme.org/IIMER-Newslet-1806-01.shtml

Invest in ME Research

- an independent UK charity finding, funding and facilitating a strategy of high quality biomedical research into Myalgic Encephalomyelitis
- focuses on biomedical research into ME and the education of healthcare staff, the media, government departments, patient groups and patients
- run by volunteers with no paid staff - no funding from government or government organisations
- overheads are kept to a minimum to enable all funds raised to go to promoting education of, and funding for biomedical research into, ME
- a small charity with growing number of supporters with big hearts and determination to find the cause of myalgic encephalomyelitis and develop treatments
- we have links nationwide and also internationally and facilitate international collaboration
- founder member of the European ME Alliance (EMEA)
- organises annual research Colloquium and public Conference attracting delegates from 20 countries
- to bring best education and research to bear on ME and find/facilitate the best strategy of research
- focused on setting up UK/European Centre of Excellence for ME to provide proper examinations and diagnosis for ME patients and coordinated strategy of biomedical research in order to find treatment(s) and cure(s) - http://www.cofeforme.org/centre
- the charity welcomes support for our work – www.investinme.org/donate

A Centre of Excellence for ME

The charity's proposal for a Centre of Excellence for ME was first made in 2010, after having sat in meetings with the NHS for several years - wasting time and effort where there seemed little progress in attempts to improve things for people with ME.

The concept is designed to create a hub of high-quality translational biomedical research into ME using standard and up-to-date guidelines and protocols that allow accurate diagnosis based on relevant tests. These would consist of full examinations, clinical diagnosis, translational biomedical research, clinical trials, bioinformatics, biobank(s) to allow for more research opportunities and support) and improved education and training of healthcare staff.
By using the facilities in the Norwich Research Park, the opportunity has been created for clinical trials to be carried out and a central point for medical education on ME to be established.

With the help of the Let's Do It For ME campaign our foundation research project was funded and established and began in 2013 at University of East Anglia (UEA)/Quadram Institute (QI) in Norwich Research Park. This was the first crowdfunded PhD for ME. Further projects are now underway in Norwich Research Park.

Concentrating on a Centre of Excellence hub does not mean that all research must be performed at the one location. IiMER has also been funding research and a PhD studentship at UCL.
Thanks to amazing support from **The Hendrie Foundation** B-cell research was initiated which allowed a preliminary study to be established and performed prior to the UK rituximab clinical trial. The charity had been keen to replicate the Norwegian Rituximab trial findings and, in 2012, the charity announced its intention to facilitate and fund a clinical trial of rituximab.

Dr Oystein Fluge and his team from Haukeland University Hospital in Bergen, Norway, visited Norwich in January 2017 to collaborate with the researchers from UEA/QI.

Ultimately, the Norwegian Phase III rituximab trial proved negative but much was gained by establishing necessary collaborations that are needed in such a trial and the work was not wasted. Research, at least in UK, depends on rules, regulations, ethics etc. that all have to be fulfilled.

Not often realised is that one of the biggest problems we have managed to overcome was the reluctance of established researchers to enter this field.

Now that has been achieved then we have to maintain and expand upon it.

Had the rituximab trial in Norway turned out to be more positive then we could by now have been seeing the elements of the Centre coming into play to show what could be done.
Nevertheless, new discussions are underway to achieve this.

The new building for the Quadram Institute provides new facilities and new possibilities and publicity for research into ME, and a coordinated environment where the Medical School, Clinical Trials Unit and research lab will be located together.

The Research Park is described by Quadram Director, Professor Ian Charles as follows -

"The development of this new centre, together with the other expertise and facilities located at the Norwich Research Park, puts it in a very good position to lead a UK and European Centre of Excellence for biomedical research for M.E. to provide possible prevention and solutions."
- Journal of IiME Conference Abstract 2015

As can be seen from the Quadram Institute web site ME is already firmly embedded as one of their "research targets" - facilitated by the groundwork performed already by the charity and its supporters.

The head of Quadram has spoken twice at the Invest in ME Research International ME Conference and there is a major group performing research with international collaboration taking place - encouraged and facilitated by the charity.
The collaboration with other UK and European researchers and institutes will create greater publicity and funding opportunities.
In the last year the charity has not been idle. A number of proposals and requests are being looked at and several new ideas are being developed.

We hope to be able to support an initial clinical fellowship in the research park soon.
International collaboration between researchers is underway thanks to the initiatives facilitated by the charity and researchers.
The funds raised by the charity have allowed a research group to be firmly established in the Quadram Institute that will allow clinical trials to be carried out in a state-of-the-art setting.
Invest in ME Research has, since establishing this proposal, raised in excess of £900,000 for biomedical research into ME – mainly over the last 5 years.
This has enabled new researchers to enter the field and firm collaborative links to be established between UK, European and US researchers and institutes.
All of this has been achieved without any government support.
A sustainable Centre of Excellence for ME that can build on these foundations is now an entirely attainable objective - harnessing the benefits of collaborative international biomedical research in modern facilities with world-class researchers.
We aim to continue to support development of this world-class ME research centre based in Norwich Research Park that can form a hub of European research and treatment for this disease and produce a pathway to produce huge benefits for the nation and across the world.
This will continue to influence other researchers and institutes in their perception of ME and provide a pathway for career development in researching this disease. This, itself, will allow new ideas to be formed in researching and treating the disease.
The foundations are therefore already in place to advance science and provide the promise of better treatment and possible restoration of function and lives back to a section of the community who have received very little help in the past.
We welcome all support to enable us to complete this project.

European ME Clinicians Council

One of the many failings in the way ME has been handled over the last decades has been the lack of education and specialisation in ME.

Few clinicians have been able to accumulate enough experience and the disease is treated in healthcare with little regard, partly due to this failure and the lack of funding for fundamental research.

Those clinicians who have gained experience in treating ME patients and collaborated with biomedical researchers need to be encouraged and supported.

Our international conferences and research Colloquiums have brought together researchers from around the world and been instrumental in forging new and promising collaborations.

Our European ME Research Group (EMERG) concept brought European researchers together. In a similar way, we feel it is important for experienced clinicians to share their knowledge on diagnostic and treatment methods and produce documentary aids for the research community focused on clinician guided treatment trials, identification of possible illness subsets, and observations of illness presentation.

The charity has therefore facilitated the formation of a new European clinicians group. An inaugural CPD-accredited meeting took place in February 2019 in London. The charity sought out the leading clinicians in Europe who are treating ME patients and whom we felt will be supportive and constructive in going forward for the benefit of people with ME and their families.

This meeting followed an American initiative that was started by Dr Lucinda Bateman and Mary Dimmock. We have used the name given to the American group that met in USA early 2018 under the chair of Dr Bateman and named this group the **European ME Clinicians Council** (EMECC). We have also borrowed from the USA experiences and documentation and liaised with Mary over the establishment of this group. We used the American meeting as a model and used similar objectives. We wanted to build a network of clinicians in Europe who could support each other, work together, and come together immediately.

As Dr Bateman stated, aggregating the knowledge of experienced clinicians on clinical sub topics related to ME/CFS and providing patients, caregivers, advocates, clinicians and the researchers the most up to date information is a critical outcome.

The aims of the inaugural meeting were therefore to bring together clinicians in the field of ME, to review the current state of knowledge, to present and discuss the latest initiatives, and to foster collaboration.

Since the meeting the clinicians have been working together and this has become a formal group that will work with the American initiative and be supported by the European ME Alliance (now representing fifteen countries).

This group will improve the knowledge of clinicians in Europe and act as a focal point for healthcare agencies, doctors and media outlets who wish to learn more from experienced clinicians about ME.

The next meeting has already been planned in order develop the network and it has already increased in numbers since the first meeting. The first EMECC meeting took place over three days and a very positive and progressive atmosphere was created with a range of topics being discussed covering diagnosis, treatments, follow-ups, education, research and how the group continues and expands.

One of the first items from EMECC is the following statement -

Statement from EMECC

LONDON, May 2019

International clinical and research experts participated in the first CPD-accredited European ME Clinicians Council (EMECC) workshop that took place over three days in London in February.
EMECC has been formed to bring together clinicians from across Europe and from various disciplines to develop a European foundation of high-quality clinical expertise on myalgic encephalomyelitis (ME, also known as ME/CFS).

Myalgic Encephalomyelitis (ME or ME/CFS) is classified as a neurological disease that affects patients' lives profoundly. The USA Institutes of Medicine (IOM) stated in its 2015 report that "it is clear from the evidence compiled by the committee that ME/CFS is a serious, chronic, complex, multisystem disease that frequently and dramatically limits the activities of affected patients".

In view of this, we are concerned to note the longstanding and continued promotion in many countries of the psychosocial view of this condition, whereby it is regarded as a "non-disease" caused simply by a combination of falsely held patient belief systems combined with deconditioning. In our view, this belief system has done immense harm to both the patient community and the prospects for research on this condition.

There is much misinformation for this debilitating disease where the current lack of any effective treatment aggravates patient suffering caused by mismanagement due to inadequate, and sometimes absent, policies of healthcare agencies regarding this disease. IOM state that physicians should diagnose ME/CFS if diagnostic criteria are met following an appropriate history, physical examination, and medical work-up.

EMECC aims to harvest effective strategies for patient management and treatment from the pooled clinical knowledge of physicians working extensively with ME/CFS patients. A further important aim is to provide or refine ideas for research in all aspects of the disease based on the extensive clinical, hands-on clinical experience of the EMECC members.

The meeting created a very positive and progressive atmosphere with a range of discussions around diagnosis, management and treatments, follow-up investigations, health personnel education and research and how the group will continue and expand.

Arranged by UK charity Invest in ME Research and endorsed by the European ME Alliance this workshop involved leading clinicians from Europe who are treating ME/CFS patients and who will be instrumental in creating a sea change in clinical care for the benefit of people with ME and their families. The group will fill a vacuum in clinical expertise that has allowed false beliefs about the real nature of the disease to be propagated.

This group will continue to meet in locations across Europe for follow-on meetings and be able to play an important role in clinical care, biomedical research and guidelines development.
The workshop was CPD-accredited and we look forward to this group of clinicians/researchers making huge progress in developing sound clinical care for ME/CFS patients - and with the collaboration with our colleagues in the European ME Alliance.

European ME Clinicians Council
For more information, please contact info@euro-me.org or info@investinme.org

THINKING THE FUTURE

Encouraging Young Researchers

In highlighting some of the issues with ME a major problem is the lack of biomedical research into ME and the funding required for it. Another issue with ME that the charity has been attempting to resolve is the need for new research talent to enter the field.

Medical students receive extremely poor education on ME in their curriculum - sometimes even nothing.

Not only might this be negligent, as young doctors are subsequently unqualified to deal with ME, but it also means that potential recruits to ME research and treatment positions are discouraged due to ignorance of the condition. Medical students are unaware of the career opportunities.

One way to get around this problem was to make students aware of the research that was being undertaken.

With the help of the University of East Anglia Medical School the charity was able to fund and facilitate the participation of a number of medical students in the research being performed at Norwich Research Park. The idea was to fund the inclusion of medical students in research via a process of intercalation during their fourth year of medical studies. This led to collaboration with research at Oxford University with Professor Angela Vincent and with Dr Lesley Hoyles at Imperial College London.

This has proven to be very successful.

Apart from influencing opinions of their peers the medical students have been very active and well received in the research teams.

Navena Navaneetharaja was one medical student funded by IiMER and Navena spent time with Professor Maureen Hanson at Cornell University in Ithaca, New York - developing another of IiMER's strategies in forging international collaboration in research.

Thinking the Future network

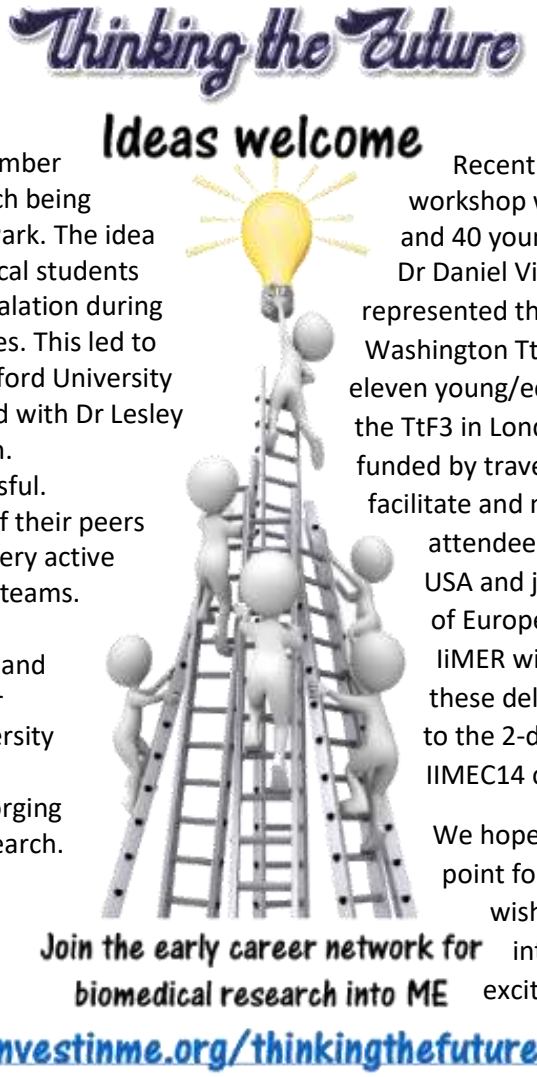
To ensure that a foundation of biomedical research into ME can be sustained and to encourage new ideas from new areas then we cannot rely just on this family of researchers that has been built up from all parts of the world at Colloquiums.

We need to draw in knowledge and expertise from other areas – as we have been doing for many years with our research Colloquiums and international Conferences. Importantly, we also need to encourage early career researchers – and young researchers.

In 2018 the charity initiated the young/early career researcher conference - **Thinking the Future** - an initiative to build a network of new and young research capacity for the future.

The Thinking the Future network has the opportunity for developing this group of international, early career researchers which will, in turn, facilitate further international collaboration in research into ME and new ideas being formulated.

In fact we have already had several meetings with NIH to collaborate on developing this network.



Recently the Thinking the Future workshop was held by NIH in Washington and 40 young/ecr researchers attended. Dr Daniel Vipond from Quadram Institute represented the charity and spoke at the Washington TtF event. We are happy that eleven young/ecr investigators will be attending the TtF3 in London in ME Conference Week - funded by travel awards from NIH. We wish to facilitate and maximise the easy networking of attendees in order to build the network in USA and join it with the established group of European young/ecr researchers so IiMER will cover all registration costs for these delegates – to the TtF workshop and to the 2-day Colloquium and the public IIMEC14 conference.

We hope this initiative will provide a focal point for all young/ecr researchers who wish to become involved in research into ME and help describe the exciting career path that this could become.

Denmark - Ærlighed varer længst

(HONESTY LASTS LONGEST)
DANISH PARLIAMENT SEPARATES ME G93.3
FROM FUNCTIONAL DISORDERS

Following excellent work by European ME Alliance-Denmark member Dansk ME Foreningen, and work and input by those such as European ME Clinicians Council member Dr Jesper Mehlsen, there is now unified support in the Danish parliament for separating ME G93.3 from Functional Disorders and acknowledgment that the existing treatment of ME patients is inadequate and stigmatising.

Specialist services are needed and the Department of Health needs to update its guidance regarding ME. Voting on the adoption of this proposal took place on Thursday 14th March.

The Danish parliament voted unanimously for the separation of ME WHO ICD-10 G93.3 from Functional Disorders and called for the Department of Health documentation to be amended to reflect this.

This discussion in the Danish parliament on classifying ME as a somatic and not as a functional disease is good progress. It was based on the case of a 29-year-old woman who has been lying in bed in a dark room since 2015, being taken care of by her parents without any help from the Danish healthcare system.

Both the Danish ME organisation and Dr Mehlsen had been in contact with a number of politicians on both sides of the aisle and the results are positive. The Danish parliament voted unanimously in favour of ME as a somatic disease to be removed from the centres of functional diseases.

That will be a great relief for the family concerned, for physicians, and for the Danish ME community.

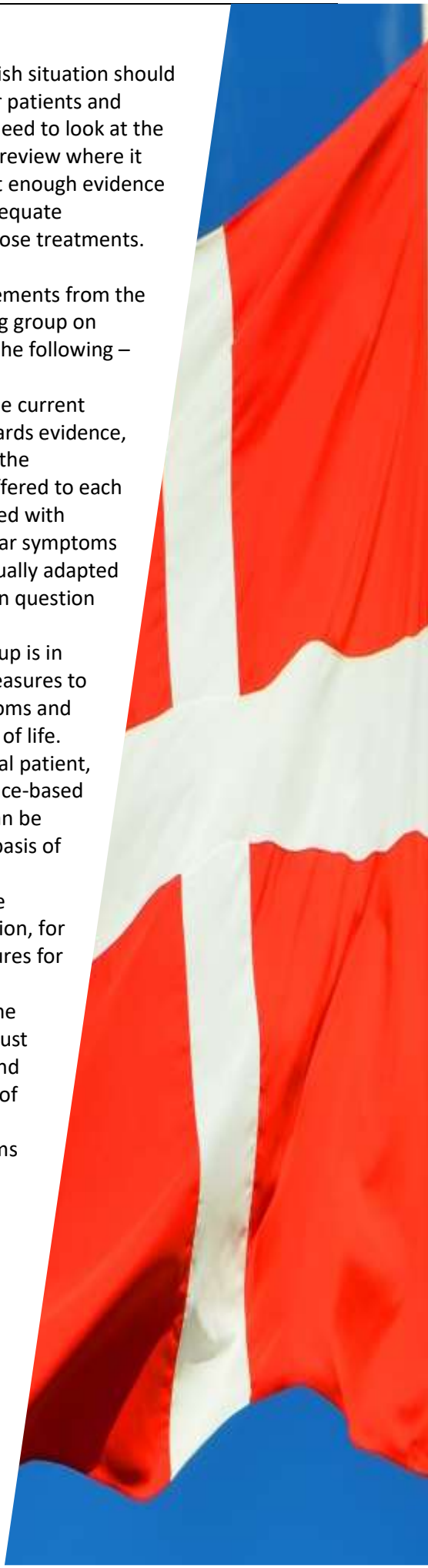
The result should help Finland too, as a team at Duodecim (Finland's largest scientific association) has been formed to look at Finnish guidelines and there was a proposal to adopt the previous Danish position.

That cannot happen now and the Finnish authorities must change course accordingly.

In fact, the Finnish situation should be improved for patients and Duodecim will need to look at the recent Swedish review where it says there is not enough evidence to formulate adequate guidelines/propose treatments.

One of the statements from the Swedish working group on guidelines was the following –

" Considering the current situation as regards evidence, it is crucial that the interventions offered to each patient diagnosed with ME/CFS or similar symptoms must be individually adapted for the patient in question and evaluated.
This patient group is in need of care measures to alleviate symptoms and improve quality of life.
For the individual patient, different evidence-based interventions can be offered on the basis of the symptoms presented in the patient in question, for example, measures for pain or sleep disturbances. The care provider must be perceptive and take all aspects of the patient's medical problems and healthcare needs into account."



UK - Parliamentary Debate

In UK a parliamentary debate in the main chamber held on 24th January 2019.
The person responsible for getting all of this started, a supporter of IiMER, was a constituent of SNP MP Carol Monaghan who put forward the debate.
This followed on from a previous parliamentary debate held in June 2018 on the PACE Trial.

The debate was entitled - "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."

IiMER made a document - **The Debate is Over – Give ME Patients a Future** - covering some of the issues relating to the parliamentary debate on 24th January 2019. This is available on our web site.
In this summary the charity called for the following-

- A Public Inquiry into ME
- Implementation of revised CMO Report Recommendations
- Removal of Existing NICE Guidelines for ME immediately
- An annual Report to Parliament of the Status of ME
- Transparency of Meetings Concerning ME by MRC
- Removal of Those Previously Responsible for ME from positions of Influence
- Research Funding - A five-year, ring-fenced budget of £20 million per year for biomedical research into ME should be allocated
- Guidelines for diagnosis must be as accurate as possible and must be up to date
- The CMOs of UK Must Report Annually on Prevalence of ME in UK
- Patients Diagnosed with ME Need a Regular Follow-up Pathway
- NICE Must Follow Department of Health View of ME
- A specialism consultant needs to be established for ME
- Medical curricula need to be revised education needs to extend to social care
- Schools need to be educated about ME

There are some clear signals for what needs to be done – as always we look for actions to replace words.

NICE National Institute for Health and Care Excellence

In 2018, IiMER carried out an extensive correspondence with the then director of NICE guidelines Professor Mark Baker. We made the case for removing both Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET) as recommendations from the existing NICE guidelines immediately - whilst a new review was underway.

This obvious necessity to remove recommendations which harm patients, something IiMER has called for consistently and which most now agree with, was met with disingenuous arguments from NICE as to why they would not be removed.

The NICE review of guidelines for ME has now produced a guidelines working group. This has already been criticised by many for creating a "balance" between those who have a disposition to a Biopsychosocial view of ME, and those who believe ME to be a biomedical condition.
The shambles of development group selection process reached farcical proportions during the setting up the group, with piecemeal announcements being made as to who had been selected for the development group and who had not, and background lobbying being conducted to get special places for certain individuals in this working group. The lack of transparency in the selection process was typified by the situation whereby some people who had applied to the working group and had been rejected could nevertheless conveniently be found a position connected to the working group. It demonstrates that the whole selection process is flawed.

NICE has politicised this whole process where there was no need and really cannot be trusted. There are obvious conflicts of interest still left in place in this

group where positions seem to be able to be negotiated. A “balance” was created where no “balance” was necessary.

The Centre for Guidelines (CfG) develops guidance based on -

- the promotion of good health
- the prevention of ill health
- the appropriate treatment and care for people with specific diseases and conditions
- social care and service delivery

We contend that retaining the existing guidelines – especially the recommendations for CBT and GET that are known to harm patients – is not promotion of good health. We also contend that retaining these recommendations is not preventing ill health.

We provided a letter to Professor Baker from an ME patient who was a civil servant and who clearly described the harm done by CBT and GET. Professor Baker’s response was that the existing guidelines had “nuances” (nuances only perceived by Professor Baker it would seem) that apparently meant that patients did not have to accept CBT or GET. The fact is that insurance companies force people to go through these shambolic treatments precisely because they are recommendations by NICE.
NICE seem to think that it would be possible for patients suffering from ME to have the capacity (either physically or financially) to fight the might of insurance companies. The level of puerile thinking on the part of NICE is unconscionable.

The opportunity to withdraw these irresponsible recommendations from the existing guidelines has been lost and we are left with a shambolic working group selection process that augurs badly for the future.
NICE could have removed the politics from this topic if it had approached the whole review with transparency. Now we are left with a compromised working group full of self-interest and conflicts of interest and we can only foresee another wasted opportunity and a fudges being formed for publication in 2020 that will serve nobody.

At least NICE must accept all responsibility for any harm caused to patients who are forced into trying CBT and/or GET due to NICE retaining the existing recommendations for CBT and GET.

Hopefully, other developments that may come to fruition over the next year will leave these farcical NICE tactics as a redundant relic from the past.
One wonders what NICE can really imagine will be available for their review. The IOM carried out an extensive literature review in their 2015 report. Recently the Swedish authorities have examined ME. Their report follows – and it is doubtful that in one year NICE will deliver anything original – unless they remove CBT and GET completely, as many other countries have done or are doing.
What NICE could have done is review the recent analysis by Sweden and their National Board of Health and Welfare.

Sweden

From Article number 2018-12-48 1(2)

A review of the current knowledge status for Myalgic encephalomyelitis/chronic fatigue syndrome, ME/CFS

Summary

Socialstyrelsen (National Board of Health and Welfare) has been tasked by the Government to review the knowledge status and examine the prerequisites for providing support to healthcare professionals through guidelines and insurance medicine decision support (FMB) with regard to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).
Patients with ME/CFS have autonomous, cognitive and immunological symptoms. Typical symptoms are tiredness or fatigue, influenza-like symptoms with a feeling of fever, general pain in joints and

muscles, and disturbed sleep. The symptoms can be exacerbated by physical or mental exertion and the worsened state continues for more than 24 hours afterwards (post-exertional malaise, PEM). Descriptions of this disorder have existed since the 1950s. There are many hypotheses about what causes ME/CFS but up to now it has not been possible to prove any of them. Research is being done but currently there are no biomarkers for diagnostics, nor any medical treatment. The prevalence of ME/CFS depends on what criteria have been used and how data have been gathered. The figure varies from 0.1 percent to 6.4 percent of the population.

When it comes to opinions regarding the cause of ME/CFS and its treatment, there are different standpoints: those who support a bio-medicinal view and those who support a biopsychosocial view. The question is whether the disorder should be explained purely through pathological biochemical and physiological findings, or whether mental and social factors must also be included in order to be able to explain certain medical problems.

ME/CFS is an exclusion diagnosis. There are no biomarkers. Instead, the diagnosis is made with the help of diagnosis criteria that are only used when other physical or mental causes of the symptoms have been excluded. There are several different diagnosis criteria that overlap one another in part and there is no international consensus about them. There are also different standpoints regarding what illnesses/disorders are to be excluded before the di-agnosis is made, and what comorbidity may exist.

Patient representatives have pointed out the need for equal healthcare, guidelines and specialist care for this group. Patients' experiences of healthcare vary both at individual level and according to geographical location in Sweden. Patients have also pointed out the need for more understanding treatment by healthcare professionals and for coordinated interventions.

An overview of qualitative studies from SBU (Swedish Agency for Health Technology Assessment and Assessment of Social Services) regarding how adult patients diagnosed with ME/CFS perceive the care they are given shows that diagnosis, advice and support are essential. The patients have described the journey to a diagnosis as being cumbersome and that they have had to fight in order to get help. They feel that people are not interested in their problems and that healthcare professionals at primary care level do not believe the illness exists.

Socialstyrelsen's dialogue with the healthcare professional groups in question has shown that there is a certain demand for national guidelines and insurance medicine decision support. However, specialists in general medicine seldom meet patients with ME/CFS, and no specific specialist field feels they have special responsibility for this patient group. This shows that these patients do not have any proper "home" in the healthcare system.

The systematic overview conducted by SBU indicates that the scientific sup-porting documentation for the interventions offered in the relevant studies is insufficient. In addition, Socialstyrelsen's survey shows that it is not possible to draw conclusions about the benefit of those interventions on the basis of proven experience since the prerequisites for consensus among clinical experts in this field are lacking. Therefore, Socialstyrelsen's assessment is that it is currently not possible to draw up national guidelines with general advice in this area, as requested by the healthcare sector.

Moreover, the basic preconditions for further work on insurance medicine decision support (FMB) for the diagnosis of ME/CFS do not exist.

Socialstyrelsen emphasises that being on sick leave can be a correct intervention but no general recommendations can be given.

Considering the current situation as regards evidence, it is crucial that the interventions offered to each patient diagnosed with ME/CFS or similar symptoms must be individually adapted for the patient in question and evaluated. This patient group is in need of care measures to alleviate symptoms and improve quality of life. For the individual patient, different evidence-based interventions can be offered on the basis of the symptoms presented in the patient in question, for example, measures for pain or sleep disturbances. The care provider must be perceptive and take all aspects of the patient's medical problems and healthcare needs into account.

The systematic overview and the qualitative report from SBU and this review by Socialstyrelsen can provide the healthcare sector with an up-to-date picture of the knowledge status, and indicate the need for more interventions and research for this patient group. Socialstyrelsen's intention is to facilitate a dialogue between representatives for different professions in order to increase consensus in the long term.

Here is the English version of the summary https://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/21182/2018-12-48-summary.pdf

Myalgic encephalomyelitis and Chronic Fatigue Syndrome (ME/CFS) - A systematic review

sbu policy support
december 2018 | www.sbu.se/295e

Summary

Aim

The aim of this report was to investigate the available body of evidence for the treatment and prognosis of ME/CFS as well as a review of the health care experiences of patients.

Background

Myalgic encephalomyelitis, also called Chronic Fatigue syndrome (ME/CFS), was first described 70 years ago. The disorder often is preceded by an infection but the pathology and mechanisms behind ME/CFS are still unknown. People with ME/CFS can suffer from a broad spectrum of symptoms, e.g. prolonged fatigue, pain and post-exertional malaise (PEM). Individuals with ME/CFS have decreased activity levels and can have difficulty handling their everyday day duties, work, or studies and maintaining social relationships. For some, the symptoms can be so severe that they are home-or bedbound.

There are no biomarkers for ME/CFS that can be used for diagnosis. The criteria for diagnosis have therefore developed over the years and are consensus-based sets of core symptoms. All the criteria include newly-onset severe and persistent fatigue and stipulate that core symptoms must have persisted for at least 6 months. The newer Canadian Consensus Criteria differs from previous criteria in that PEM lasting at least 24 hours after physical or mental exertion is required for a diagnosis. By applying the Canadian Consensus Criteria, the prevalence of ME/CFS is estimated to be about 0,1% of the population.

Differentiating between ME/CFS and other diseases with long lasting fatigue, e.g. stress related exhaustion disorder, can be difficult. Studies show that half of patients referred to specialist clinics for suspicion of ME/ CFS were shown to have other diseases after closer examination, mostly sleep or psychiatric disorders.

There is no curative treatment for ME/CFS. Health care therefore aims at relieving symptoms and supporting the patients in the management of their everyday lives.

Content of the report

This report is made up of four systematic reviews, conducted according to international guidelines. The first systematic review focuses on treatments and their effects on fatigue and PEM for persons with ME/CFS diagnosed with the Canadian Consensus Criteria. Treatments that aimed at relieving other symptoms, e.g. sleep problems or pain, or psychological therapies aimed at helping patients manage their disease were not included. Included studies were controlled clinical trials, with or without randomisation.

The second systematic review assesses prognosis for recovery and return to work, while the third investigates whether there are any prognostic factors for improvement and return to work. In the fourth systematic review, we explore how patients experience their health care by reviewing studies that used qualitative methods, such as interviews, to address this question.

The report only includes studies on adults.

Main results

A major finding was that the effects of treatments for patients diagnosed with the Canadian Consensus Criteria on fatigue or PEM cannot be estimated. Most studies used older criteria, mainly the Fukuda criteria, meaning there is a risk that the participants in the studies had other conditions, such as stress related exhaustion disorder or depression. Whether these results are valid for persons diagnosed according to the Canadian Consensus Criteria is therefore unclear.

A small number of studies, most investigating pharmaceutical treatments, used the Canadian Consensus Criteria. None of these studies reported that the drug reduced fatigue.

The prognostic studies identified applied older criteria. Two studies conducted in Scandinavian countries reported that a substantial proportion of the participants had not recovered at follow-up, around 10 years after symptom onset. One English and one Norwegian study found that many patients who had been diagnosed in specialist clinics after several years of disease and unemployment, had not yet returned to work or study at follow-ups conducted many years later. Prognostic factors for recovery or return to work could not be evaluated

as there were few studies, which were small and had substantial methodological limitations.
The qualitative studies mostly described patient experiences in primary care. Many perceived that getting a diagnosis was a milestone and that individually tailored support was crucial for them to move on with their lives. They experienced the process of obtaining a diagnosis as burdensome and frustrating and felt that they were met with ignorance and lack of understanding.

Discussion
This report shows that there are many scientific evidence gaps regarding ME/CFS. Many gaps, such as methods for diagnosis and efficacy of curative or disease modifying treatments, are related to the lack of understanding of the aetiology behind ME/CFS.
This report also indicates that a thorough diagnostic work-up is crucial. Multidisciplinary specialist competences are necessary to reliably exclude other disorders.

Finally, the absence of evidence for effect of ME/CFS treatments does not mean that the treatments lack effect, but rather indicates that research is needed to clarify the effects of current treatments for people diagnosed with ME/CFS according to the Canadian Consensus Criteria. Meanwhile, it is important to support people with ME/CFS so they can attain the best quality of life, levels of function and participation in society as is possible. Since ME/CFS is relatively uncommon compared to other similar disorders, e.g. stress related exhaustion disorder or chronic pain, specialist clinics for ME/CFS would probably be advantageous, as they would be most likely to be able to closely follow the research and quickly implement new developments into clinical practice.

Project group
Experts
Per Julin, MD, PhD, Karolinska Institutet, Stockholm, and the ME/CFS-clinic, Stora Sköndal
Per Lytsy, MD, Assistant Professor, SBU
Marie Åsberg, Professor, Karolinska Institutet and Danderyd Hospital, Stockholm (advisory role in assessing differential diagnoses)

SBU
Agneta Pettersson (Project Manager)
Susanne Gustafsson (Information Specialist)
Caroline Jungner (Project Administrator)
Lina Leander (Assistant Project Manager)
Hanna Olofsson (Information Specialist)

Scientific reviewers
Kristina Bengtsson Boström, Skaraborg
Kristina Glise, Göteborg
Björn Mårtensson, Stockholm
Anne Söderlund, Västerås

SBU Assessments no 295e, 2019 www.sbu.se/en • registrator@sbu.se English Proofreading: Rebecca Silverstein, SBU Graphic Design: Åsa Isaksson, SBU

Perceptions of Care in a Hospital's Emergency Department

A very useful recent paper published by Timbol and Baraniuk discusses Emergency Department visits by ME/CFS patients.

"CFS patients present to the ED with a complex list of chronic symptoms, but the acute reasons for presentation are related to orthostatic intolerance, fatigue, PEM, and diarrhea."

Professor James Baraniuk - Professor of Medicine at Georgetown University Medical Centre, Washington, USA - is a regular at IiMER colloquiums and conferences and always has very interesting and useful contributions.

"This is of importance because it provides a starting point for diagnosis and treatment by ED physicians," Baraniuk said.

"This condition is something that can be readily addressed by ED caregivers," he said.
"There is a real need for physician education that will improve their efficiency in identifying and treating CFS, and in distinguishing CFS symptoms from other diseases in the exam room."

"These patients should feel they are respected and that they can receive thorough care when they feel sick enough to go to an ED," Baraniuk said in a Georgetown news release."

Here is the abstract.

Chronic fatigue syndrome in the emergency department

Available from DovePress
https://www.dovepress.com/chronic-fatigue-syndrome-in-the-emergency-department-peer-reviewed-fulltext-article-OAEM
Christian R Timbol,* James N Baraniuk*

Division of Rheumatology, Immunology and Allergy, Georgetown University, Washington, DC, USA

*Both authors contributed equally to this work

Purpose:
Chronic fatigue syndrome (CFS) is a debilitating disease characterized by fatigue, postexertional malaise, cognitive dysfunction, sleep disturbances, and widespread pain. A pilot, online survey was used to determine the common presentations of CFS patients in the emergency department (ED) and attitudes about their encounters.

Methods: The anonymous survey was created to score the severity of core CFS symptoms, reasons for going to the ED, and Likert scales to grade attitudes and impressions of care. Open text fields were qualitatively categorized to determine common themes about encounters.

Results: Fifty-nine percent of respondents with physician-diagnosed CFS (total n=282) had gone to an ED. One-third of ED presentations were consistent with orthostatic intolerance; 42% of participants were dismissed as having psychosomatic complaints. ED staff were not knowledgeable about CFS. Encounters were unfavorable (3.6 on 10-point scale). The remaining 41% of subjects did not go to ED, stating nothing could be done or they would not be taken seriously. CFS subjects can be identified by a CFS questionnaire and the prolonged presence (>6 months) of unremitting fatigue, cognitive, sleep, and postexertional malaise problems.

Conclusion: This is the first investigation of the presentation of CFS in the ED and indicates the importance of orthostatic intolerance as the most frequent acute cause for a visit. The self-report CFS questionnaire may be useful as a screening instrument in the ED. Education of ED staff about modern concepts of CFS is necessary to improve patient and staff satisfaction. Guidance is provided for the diagnosis and treatment of CFS in these challenging encounters.

Medical Education

Education about ME has been one of the major objectives for Invest in ME Research.
Dr Nina Muirhead and students at Cardiff University have been working on medical education.
Invest in ME Research invited them to present poster presentations at the IIMEC14 conference in London.
The studies demonstrate the following –

1) What is the Impact on Quality of Life of Family members with ME/CFS using the internationally validated QHOQUOL-BREF and FROM-16?

Needless to say results show the negative impact of ME/CFS on family members is greater than any other medical condition.

2) What should medical students be taught about ME/CFS?
This explores current teaching in 22 medical schools UK wide and uses qualitative information from patient surveys to make recommendations for not only what should be taught but how and when this could be delivered in the undergraduate medical school syllabus.

3) What is the role of the GP in care of ME/CFS patients in the community?

This study draws together patient opinions in the form of 690 patient survey responses plus detailed ideas from qualitative analysis of telephone interviews of patients with a range of illness severity and duration. The patient voice is increasingly used in guideline development.

We include here the abstracts for these presentations.

The Impact of ME/CFS on the Family: Measuring Quality of Life (QoL) using the WHOQOL-BREF and FROM-16 Questionnaires

Brittain EL, Muirhead NL, Finlay AY and Vyas J.

ABSTRACT

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a chronic condition characterised by a multitude of symptoms, ranging from post-exertional malaise to cognitive difficulties. ME/CFS has been shown to significantly reduce patients' quality of life (QoL) when compared to both healthy controls and patients with other chronic illnesses. To our knowledge, our study is the first to explore the impact of ME/CFS on QoL of both adult sufferers and their family members using the validated questionnaires: World Health Organisation Quality of Life - Abbreviated Version (WHOQOL-BREF) and Family Reported Outcome Measure (FROM-16).

The study information was posted on the website and social media pages of the charity WAMES (Welsh Association of ME & CFS Support). A total of 39 volunteers expressed an interest in participating in the study and were posted a questionnaire pack containing one WHOQOL-BREF and four FROM-16 questionnaires. People with ME/CFS completed the WHOQOL-BREF and up to four of their family members completed the FROM-16 questionnaire. 29 participants returned the questionnaire packs (74% response rate), of which 5 were excluded due to incomplete data or not meeting the inclusion criteria.
There was a negative effect on quality of life for both people with ME/CFS and their family members. People with ME/CFS, on average, scored substantially lower in the 'Physical Health' domain of the WHOQOL-BREF and scored highest in the 'Environment' domain. Conversely, the higher the FROM-16 score, the greater the adverse QoL impact on family members. FROM-16 total scores showed that the impact on QoL was very high (mean=19.86 SD=7.17 n=42) compared to previous studies of family members of patients with other diseases (mean=12.28, SD=7.47, n=120) and cancer (mean=11.75 SD=5.85 n=248). For people with ME/CFS: there was a strong correlation between health satisfaction and their perception of their QoL (r_s=0.50, p=0.013) and none were 'satisfied' with their health nor rated their QoL as 'good'. A significant correlation was found between the QoL of people with ME/CFS and their family members' mean FROM-16 total score (r_s=-0.41, p=0.047, n=24).
This study has for the first time used FROM-16 to measure the impact of ME/CFS on the QoL of adults and their family members and highlights the need for additional larger-scale research into this area. The results of this study emphasise the importance of ensuring support is widely available to the family.

Understanding the Role of the General Practitioner in Caring for Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in the Community

Allwright EG, Muirhead NL

Background
Patients with ME/CFS are reliant on their GP for a diagnosis and early management but also holistic support, particularly where secondary services are limited. There has been increasing recognition of the importance of the patient voice. This study aimed to gain a better understanding of the patient perspective of GP care of ME/CFS with a view to identifying ways of improving the patient experience.

Methods
Information was gathered from: 1) an online question answered by 690 members of the ME Association 2) 47 written responses to this question 3) ten semi-structured interviews with patients with a diagnosis of ME/CFS. Qualitative, thematic analysis of both the written feedback and interview transcripts was used to identify themes.

Results
The online question demonstrated that patients prioritised the importance of GPs having an understanding of the symptoms of ME/CFS in order to make a diagnosis. Five themes were identified from the online free text responses and nine themes from the interviews. These covered the role of a GP in diagnosing and managing ME/CFS; the patients' perception of their GP's knowledge of ME/CFS; the broader role of the GP with links to social care and support to claim Disability Allowances; and patients' reports of the relationship between patient and GP. The data also supported the concept of having a designated healthcare practitioner, be it a GP, therapist or practice nurse, who could offer consistent care and support.

Conclusion
Participants believed that their GPs did not have sufficient resources or knowledge to best manage ME/CFS however this was deemed less important to patients than a willingness to listen and sympathise with the patient, to understand their individual experience and work in collaboration with them towards recovery. Overall, participants emphasised the perception that a supportive GP, who is honest and open with patients, can make a significant impact, regardless of their ability to cure the patient; "you hope you have a supportive GP because he will help you, even if he can't treat you, he will help you".

What Should be Taught to Medical Students about Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?

Lavery GE and Muirhead NL

Introduction:
The lack of understanding of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) amongst health care professionals has been shown to cause delayed diagnosis, misdiagnosis and harm to people with ME/CFS (PWME). There is a paucity of data surrounding teaching on ME/CFS in UK medical schools. A small study undertaken in 2012 demonstrated that UK medical students 'were unconfident and uncertain around their understanding of CFS/ME, held varying models of aetiology of the illness and had limited knowledge of the symptoms and suitable management strategies'. A larger study conducted in the USA showed that only 28 percent of medical schools met the curricula criterion for ME/CFS teaching.

Methods:
1) A quantitative analysis examining current teaching on ME/CFS at UK medical schools was performed. All 34 undergraduate medical schools in the UK were invited to complete an online survey through the website 'SurveyMonkey', 22 medical schools (65%) completed the survey by the deadline. 2) A qualitative analysis exploring PWME's perceptions of important topics to teach medical students was subsequently performed. PWME were invited to respond to a post on the Welsh Association of ME & CFS patient charity website (WAMES), entitled "What should medical students learn about ME?". Thematic analysis applied both manually and using NVIVO 11 software identified key themes.

Results:
1) Medical schools were able to skip questions if the answer was unknown. Data from the survey showed that 11 of 19 medical schools include formal teaching on ME/CFS in their curricula, the majority of whom deliver this teaching in lecture format. Only 3 of 12 medical schools spend more than two hours teaching on the topic and 2 of 10 include clinical contact with PWME. Only 5 of 19 include question(s) on ME/CFS in formal exams. Most

medical schools expressed an interest in receiving videos, e-learning and lecture materials on ME/CFS. 2) Thematic analysis of 38 written responses from PWME identified three key themes that PWME believe medical students should be taught about: i) the definition and diagnosis of ME/CFS; ii) treatment options; and iii) the ways in which ME/CFS affects quality of life (QoL).

Conclusion:
The creation of e-learning or a short video to introduce ME/CFS followed by lectures or a team-based learning approach are suggested to improve teaching of medical students on the topic of ME/CFS. It was also concluded that a comprehensive basis for medical student ME/CFS teaching relies on a curriculum that encompasses accurate up to date information on the epidemiology, terminology, aetiology, treatment and effect on QoL of ME/CFS.

Doctors and Patients

Many ME patients, at least those who are still being treated by a doctor, often comment on how doctors do not understand the disease.
This itself compromises the future prospects for a patient to receive anything approaching adequate care.
The reasons for this may be that doctors receive no training on ME - either during medical school due to flawed and sparse contingency in the medical curriculum for ME - or later during their career where there is little on offer.

Invest in ME Research has, since 2006, been arranging CPD-accredited conferences for professionals in London and the participation of doctors has been gradually increasing. Yet there remains a great deal to do.

Medical education about the realities of ME is essentially missing - with what is on offer being either inadequate or incompatible with the true requirement to understand this disease and be aware of what can make patients worse.
Doctors also may be constrained by NICE guidelines in what they feel they are able to offer.
NICE guidelines are currently being reviewed yet the farcical set up of the guidelines development group augurs badly for any positive outcome.
NICE's refusal to remove CBT and GET immediately from the existing guidelines, despite being presented with evidence of the damage caused, is negligent.

There are also doctors who clearly remain ideologically challenged by this disease and continue to harbour false views about ME, fed by a Biopsychosocial (BPS) influenced healthcare system. Above all doctors seem to have lost any ability to say, "I don't know what is wrong" - as though this may be a shortcoming.

So much easier to assign a diagnosis of the spurious Functional Neurological Disorder (FND).
If only doctors would say, "I don't know what is wrong but will work with you to find answers".
If only patients were believed.

Much of this can be traced back to negligent policies from governments, health departments, research councils and clinical care organisations, and research funding bias that discourages biomedical research into ME.

Despite this, there have been signs of light coming through as more education and more research, funded by organisations like Invest in ME Research, changes the barren landscape that has existed in the UK healthcare system.

And there are doctors who think for themselves and listen to their patients.
And there are pioneers in treating people with ME.

Two such doctors were Dr John Richardson and Dr Irving Spurr.

Dr John Richardson had a distinguished career as a physician and published numerous papers.
He was a founder member of the Newcastle Research Group in which he was very active and the primary organiser of their annual international conferences. He was also a member of the Melvin Ramsey society and the Environmental Medicine Association as well as other medical research organisations.
Following his retirement from the NHS, he continued to see patients privately on a voluntary basis regularly seeing in excess of thirty per day. Many travelled considerable distances from the UK

and abroad for his specialist advice and treatment and frequently were referred by hospitals and their own doctors.

Dr Irving Spurr was a GP in the rural Weardale Practice in County Durham for 28 years until his retirement in 1997.

He was committed to doing his very best for his patients and this led him to become a pioneering researcher into ME. During the early Eighties, a boy of 14 came to see him with all the symptoms. Irving wanted to get to the bottom of what was causing it, but ME was, at the time, belittled in NHS circles as not a 'real' condition (some would say little has changed).
He became heavily involved in the fledgling John Richardson Research Group, a medical charity in the north-east of England, ultimately leading its work to promote greater understanding and awareness, as well as more effective treatment.

His commitment included running ME clinics, with his nurse wife Eileen at his side, but it was extended to delivering lectures all around the country and building links with colleagues in Norway, Canada and Israel.
He continued with the clinics until the onset of the ill-health that preceded his peaceful death.
In recent years his view on ME — once a lonely one — increasingly become more accepted and mainstream, to the benefit of many sufferers from this disease. Yet he never let his crusade for ME cause him to short-change his other patients.

The John Richardson Research Group made a wonderful donation to Invest in ME Research to continue to establish a national and international centre for ME and translational medicine in this area.

Listen to the patients

Stories of ME

Over the years Invest in ME Research has received many stories of people enduring ME, and who have experienced the lack of knowledge about the disease, the ignorance.

Some long stories, some short.

All underlying the incomprehensibility of retaining the status quo in terms of research, treatments and services – that has suited some organisations, and individuals and benefited those taking salaries or maintaining careers based on this state of affairs.

So it is always surprising that the old adage "listen to the patients" is something often ignored.

We pointed this out in **Listen to the Patients** http://www.investinme.org/IiMER-Newslet-1809-01.shtml where it seems to go wrong, even in a country which has everything required for providing an example of how to perform research into ME, how to develop services for people with ME and how to treat ME as the organic illness that it is.

It is sobering to read some of the stories from patients, and carers – even just clips.

We alluded to some in them in the Advent Calendar Day 14 article Humour and ME article

But definitely not with any humour is the story of the family of Rose -

"The consultant said that the some of the symptoms Rose had were not due to ME (i.e. memory loss and paralysis) and that her ME could be a cloak for PRS (Pervasive Refusal Syndrome)."

from 'An ME Carer's View'
http://www.investinme.org/mestory1019.shtml

Here we have some, just a few of the many stories written or told or emailed over the years –

Some examples –

Dr D.
"I saw 2 GP's in the summer holidays. They were cold to the point of hostile when I had the temerity to suggest that I had ME/CFS."

Jim
"And because of my test results, they no longer tell me my illness is in my head, they just won't accept ME as the cause."

C
"I hope it demonstrates how utterly distressing it is for sufferers to not only cope with their ever deteriorating health, but to cope with supposedly professional people who use every opportunity to psychologically batter them into submission. "

R
""you have ME, I am not going to waste time doing tests on you" "

Julie
" I felt humiliated and ridiculed by someone who was clearly a psychiatrist of some description "

Rose
"So Rose had to do a 6 week diagnostic test for PRS with two 6-second sessions of physio, adding on 10% each week and starting with 10 minutes high activities. This included education, art therapy and visitors.
Even if Rose was unconscious from blacking out then someone had to read to her and the curtains had to remain open - 10% each week."

Sandra
"I was interviewed by this supervisor every Monday and every Friday from then on. I felt like I was a criminal. She took me into a small office and every time asked how I was doing and how long would it be before I worked full time again because I was straining the section as they had to cover for my absence"

Shelley
" I went to a Manchester hospital. That's when my nightmare began. I felt really ill at that time and a sister said it was all in my mind. "

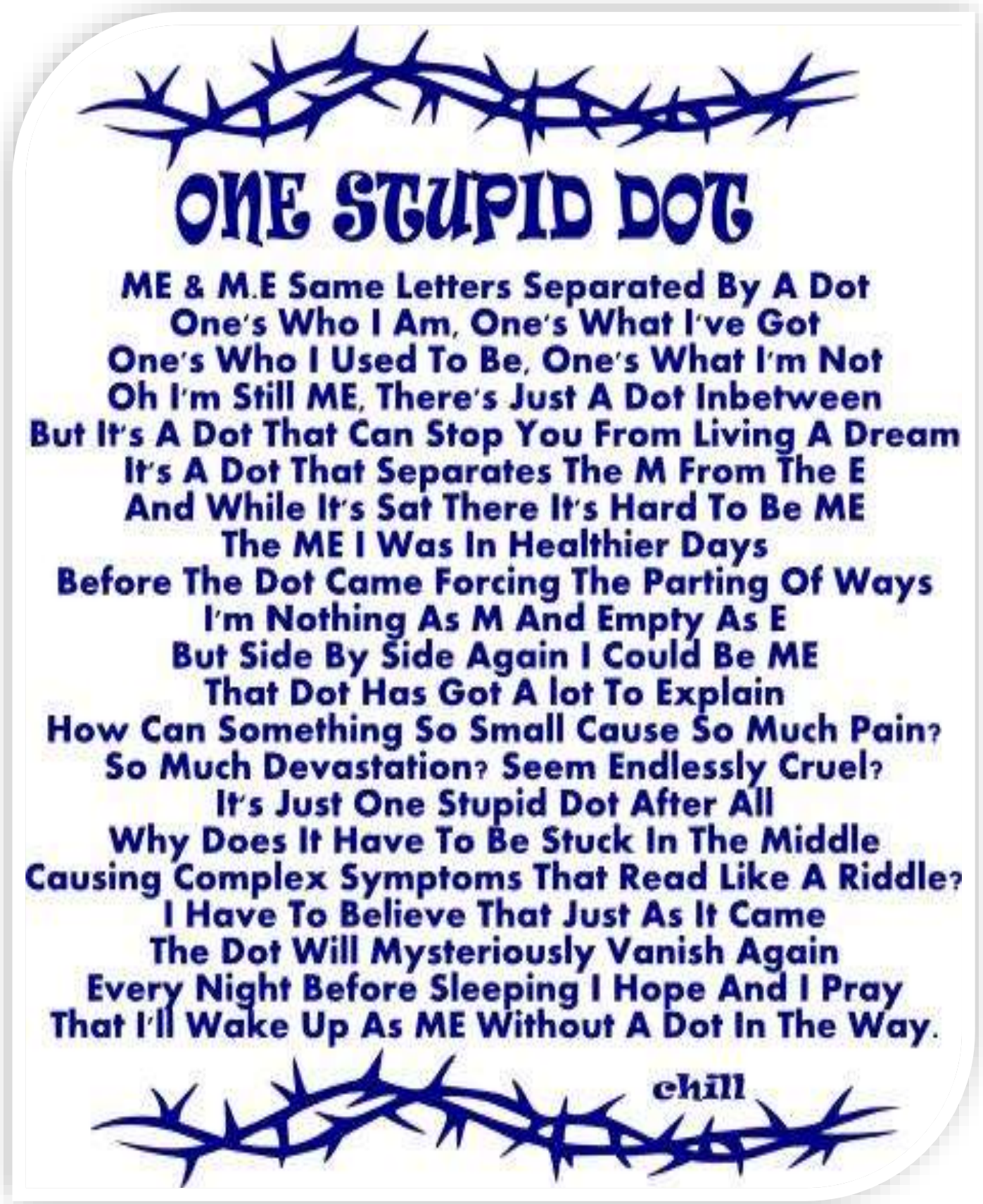
Cindy
"Being in the medical profession I am angered and embarrassed by the way I'm treated with this illness."

There are longer stories too - see Further Reading below. The stories above reflect decades of suffering and are a call for doctors and healthcare staff to believe in patients.

Healthcare staff need to remember -nobody really wants to live like this.

One Stupid D t

Stacy Hart aka ***@MamaChill*** hip hop/rap artist, diagnosed with M.E. in 1991.
Stacy still has M.E., 24 years after being diagnosed.



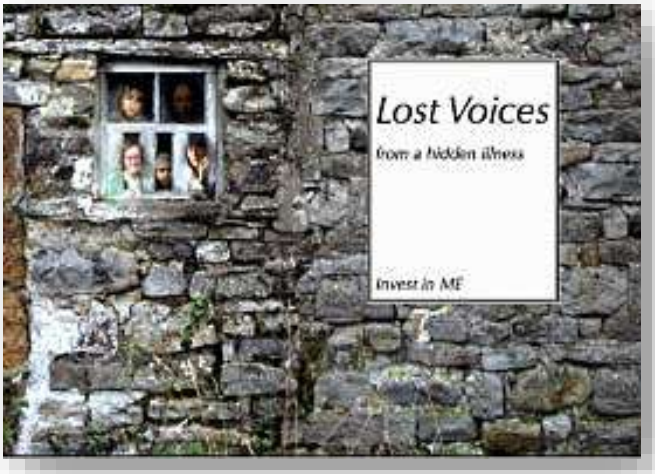
Long term illness with ME

Having ME for decades brings with it many different issues.
Apart from obvious direct effects of the illness on one's life, with the impact on family, on career, on financial situation - there are the more insidious and rarely mentioned issues - loneliness, isolation from society, further health issues with new symptoms and possible co-morbidities developing, invisible to healthcare systems due to the label of ME.

Care and compassion may also be casualties of health systems that are influenced by commercial or career interests and have no funding and no time for patients suffering from long term ME.
People who currently have had an ME diagnosis for several decades will know of all of these issues.

If a patient is "lucky" enough to receive attention then they are quite likely to be at the end of a long queue.
Healthcare systems that cannot understand the disease, let alone treat it, will have no capacity for managing the longer term consequences.

For those recently diagnosed with ME the thought of the situation getting worse, or being long-term, is something that does not initially come to mind.
Long term illness from ME is something that is not discussed much - although one can often hear of stories of those who have to endure this disease for decades.



The book Lost Voices from a Hidden illness eloquently brought out some issues regarding long-term illness.
Those patients who have had ME for several decades were young at the beginning, had dreams and ambitions, aspired to do more.

Even with their disease these long-term sufferers will have hoped for recovery, for research that brought forth treatments.

Many might also have become advocates and contributed what energy they had to changing things for the better, to raise hope that things would be different.

It is testimony to the courage and resilience of those long-term ill that they continue to hope, to campaign, to trust for a better life.
It is a sad and continuing indictment on successive governments and health departments and, especially, on research councils and their appointed guardians of research into ME that they have failed these people.

We invited Dr David Bell (Lyndonville NY, USA) to speak about his longitudinal study at our IIMEC6 conference in 2011.

Dr Bell presented his work on the 25-year follow-up of the young people from the initial illness that triggered his research.
He described this initial outbreak in 1985 in a small rural community just south of Toronto.
210 people remained ill following a flu-like illness.
Many more had the illness, but had recovered by 6 months.
Those remaining ill were finally diagnosed as suffering from ME/CFS.
60 were children and adolescents. The 13 year follow-up was written up in the Journal of Paediatrics.
80% described themselves as doing well.
Half of these still had symptoms but leading a reasonably normal life, the other half seemed OK.
20% had ongoing illness and were "disabled".

He then asked, "How should recovery be defined?" - "Is it absence of symptoms or adaptation?"
If the answer is adaptation, this leads to confusion and a false perception of health.
Factors included here would be: patient looks OK, tests are normal, specialists come up with no diagnosis and there is a lack of evolution into an illness such as MS.

This confusion is damaging for adolescents.
The current study included a follow up of 28 people, and a wide range of assessment tools was used.
3 had developed malignancies (thyroid cancer, cervical cancer and leukaemia) and were excluded.

The remainder (25) were represented by 3 groups. 2/25 (8%) were well. 18/25 (72%) had remitting illness - they considered themselves all right, but scores indicated they were not well.
The third group - 5/25 (20%) had persistent ME/CFS. They considered themselves disabled with severe symptoms and reduced activity.

These people were on disability pensions, but ME/CFS was not used as the diagnosis to be eligible, and the illness was often called other names to ensure the benefit.

Dr Bell pointed out how people do learn to adapt to this illness. Many seem to recover but then slide down again.
The worst symptoms seem to be associated with sleep and pain. He described his disability scale from 0-100 with 100 being entirely well.
Many of these patients scored around 30. He felt one of the most important questions for the clinician to ask was the number of hours of upright activity attainable each day.
In his current study, controls scored 15 hours, the persisting severe group 1-5 hours and the remitting group 13 hours.

In summary, Dr Bell concluded that at follow up 72% had mild to moderate illness, although considered themselves OK. There was health identity confusion, by remembering self being much worse, and now considering self "well". Time will tell the long-term outcome.
He felt strongly that he was looking at the natural history and course of the illness rather than any medication or vitamins promoting recovery.

The long-term ME patients constitute an area which is almost totally neglected - something that should be of major concern to healthcare providers, along with the severely ill and children with ME.

The long-term ill from ME are not only those in old age either. Younger people are included in this group if they were diagnosed with ME in their early teens.

Yet it is ignored, buried in the soundbites of the media who remain oblivious to the reality of ME; callously removed from the policies of research councils and government health departments due to apathy; unable to be researched properly due to the lack of funding from those agencies responsible for funding; and often let down by support organisations who take subscriptions but do little to convince anyone of this neglected section of society.
We can only hope that we can soon get to a situation where all people with ME will get adequate treatment based on results from well-funded biomedical research.

This subject needs to be included in debates about ME in any parliament setting. It needs to be recognised and addressed in healthcare systems. The long term ME patient needs to be represented.

In the meantime, we recognise the courage of those who have had to endure ME through many years with little or no support and yet who continue to remain hopeful and try as best they can to help to change things.

Caring for Someone with Severe ME

Issues with ME are not isolated to patients. Carers are affected - and especially so if they are caring for a severely affected patient.

http://investinme.org/18CNYadventcal08.shtml

Caring for someone with ME

"She was gradually deteriorating.
Every tiniest activity (physical, cognitive and sensory) from washing her hair to rubbish collection day, had devastating results.
Sometimes she could recover in a few days, other times it would take months, but often the cumulative effects of the noisy, smelly, bright, sunny, loud, vibrational, fast, chemical based world we live in were all too much and disease progression with permanent damage resulted.
Doctors always amaze me when they are puzzled by her severity and wonder why it's taking so long to 'pick up her bed and walk".

- Lili

It is difficult to convey fully the overwhelming effects of severe ME – on the patient or on carers. We can only allude to the horrendous course that ME can take, point out at how little has been done to address this particular issue of ME, and state what we, as a charity, are trying to do to change things.

The odds are stacked against carers if the person(s) they are caring for suffer from ME.
Carers 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.
Lack of understanding about the disease by the public – a great deal of which has been caused by misinformation from media centres and compromised media editors - can even affect relationships.
If a carer/partner does not understand the illness or has been misinformed due to the media propaganda then subsequent strains on relationships can take its toll – thus further aggravating the situation for the patient.
Apart from having to research oneself what this disease is, and what treatments there may be, a carer/parent may suddenly be met, not with compassion or understanding, but with the full force of social services intervening and suddenly becoming victim to the ignorance that pervades society.
The other insidious effects of ME that the patient experiences – such as isolation – may also come into play for carers.

Kjersti Krisner gave a moving testimony of issues with severe ME in her pre-conference dinner presentation prior to the 11th International ME Conference in London in 2016.
If one wished to see all that has been wrong with research policies toward ME by establishment organisations over the years then one would only need to see Kjersti's presentation
Kjersti's family of three severely affected children was highlighted in Norwegian TV with the NRK channel Pulse program in 2009.

Meridian TV aired a series of programmes in 2005-2006 covering the effects of ME on severely affected patients. A reporter from Meridian interviewed a number of ME sufferers in Hampshire as well as at the regional ME centre.
This set of interviews conveyed the suffering and lack of action regarding ME.

One of the most shocking and heart-breaking cases involved Sophia Mirza.
The full force of establishment ignorance about ME came crushing down on one poor girl and her family.
Had this story occurred today, with all of the effects of social media, then the story would have been a national scandal with resulting action being taken.
Instead, Sophia's mother, Criona, had to continue to campaign for years to try to get justice.

Invest in ME Research organised a conference call in 2013 with Dr Martin McShane, Director of Domain Two, NHS Commissioning Board, after a supporter contacted her constituency MP (which happened to be the Prime Minister at that time).
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.

- There was a cluster of 5 people who became ill at the same time in the small village in which they lived

- Not one GP took it upon themselves to investigate

- Life was a living hell as their child could not talk, could not swallow and was sensitive to light and noise

- Severe ME causes panic in healthcare professionals who want quick fixes, and look around

for some other causes in parents or patients (Munchausen's by Proxy, Pervasive Refusal Syndrome and so on) despite the CMO report recognising ME as an organic illness

- Good doctors who kept children safe from the threat of child protection orders have now retired or passed away so the parents have nowhere to turn to for support

- OTs were helpful but in their experience GPs had been terrible

- Advice/information given by unhelpful GPs and consultants, paediatricians over the years included removal of parental support, physiotherapy, stating that ME is not a real disease, that it was an illness caused by exam nerves etc.

- GP visits were unannounced, and the family was reported to social services for neglect and the family were then asked to leave the GP service

- In 2012, after a fairly stable period, tooth surgery caused a severe relapse and the GP decided to resurrect the earlier accusations

- The family had kept quiet for 12 years but felt now that enough was enough. They had sent complaints to PALS. The 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.
IiMER felt this was not good enough.
We explained how we had sat in countless meetings, with words said, promises made and nothing ever changes. It was unacceptable.
Empathy was fine, and we were grateful for Dr McShane's acknowledgement of the poor service given to ME patients and their families.
However, we needed to progress – and we had ways, proposals which could be used to progress this.

"The carer of an M.E. loved one is like no other carer. Not only is it imperative to learn about myalgic encephalomyelitis in order to give the specialist care required for M.E. (to avoid causing them further harm), it is also necessary to become their protector"

IiMER pointed out the difficulties in getting anything done and we did not want to go away from yet another meeting with nothing, and no action plan.
The local commissioner at the meeting had promised education of GPs.
However, we all felt that there is a major problem in the lack of accountability.
Nobody seems to want to take responsibility - and this extends from the local level right the way up the chain to the CMO and the Minister for Health.
(IiMER mentioned that CMOs had been invited to every single one of the eight (at that point in time) IiMER annual conferences - without any sign of leading or an agenda for ME)
IiMER suggested using this area (ME) as an example of a difficult area of medicine and use it as a model for nationwide services.
Dr McShane promised to promote Dr Terry Mitchell's approach (kind, caring, patient centred).
Whilst we felt Dr McShane was genuinely empathetic to the plight of ME patients and their families we saw no appetite from any direction in the NHS to invoke change, to rectify the inadequacies in the NHS or to initiate any visionary approach to progressing ME.
And so it proved to be.
At the meeting our overriding feeling was that we would have to continue to make the changes necessary ourselves.
And so it proved to be.

Dr Amolak Bansal spoke at the #IIMEC8 conference in 2103.
After the conference Dr Bansal added the following especially for Invest in ME for a forthcoming news article (which subsequently was not used), explaining severe ME in the following way -

"While it is presently very difficult for modern medicine to fully explain all severe ME symptoms, disordered neural function within the brain and spinal cord would come close.

How this occurs is unknown but there are counterparts in certain newly described autoimmune conditions and viral infections of the nervous system.

In addition to a direct stimulation of neurones in different parts of the brain and spinal cord there is

also an impaired filtering function of the brain stem and a reduced threshold for neurones to fire off.

This allows external stimuli such as movement, light, sounds, touch and sometimes even worrying thoughts to produce widespread neuronal activation with ultimate excitotoxic damage to these cells.

The consequence is impaired activity of the brain generally but particularly the hypothalamus and prefrontal cortex leading to fatigue, disordered sleep, impaired memory, attention, faintness, palpitations, disordered respiration, temperature dysregulation etc.

Outwardly, many patients appear well and routine blood and other investigations are normal.

Internally there are severe symptoms that, if unchecked, escalate leading ultimately to immobility and increasing pain and spasms in a proportion of patients.

Clearly a greater understanding of this highly disabling condition is required with a greater focus on disrupted immune and neural pathways and not just psychosocial factors as has previously been the case."

Sidsel Elisabeth Kreyberg carried out a small survey on Caring for seriously ill ME-patients that showed how important experience was in the work with ME.

Severe ME patients have not often been included in research into the disease. This may be necessary on occasions, depending on the type of research or the logistics of accessing the patients in their delicate state.

But IiMER has always stated that severely affected patients should not be excluded from research. Invest in ME Research are currently funding research into ME with severely affected patients being included.

Diane - the carer/mother of severely affected daughter Lili, eloquently described her caring for her daughter and how her whole life was lived from her bed.
Diane describes her GP "as an aggressive rude man who insulted Lili to such a degree that I wanted to throw him out".

Attempts to change things resulted in a different GP being arranged - one who visited Lili but had seemingly already prejudged both carer and patient and who was very keen for Lili to do Graded Exercise Therapy (GET).

This already horrendous situation for Lili and Diane turned ever darker when social services intervened amid doctors' allegations of abuse.

In Dianes's story of Lili Diane writes –
"The carer of an M.E. loved one is like no other carer.
Not only is it imperative to learn about myalgic encephalomyelitis in order to give the specialist care required for M.E. (to avoid causing them further harm), it is also necessary to become their protector.

This serious illness is very misunderstood, even by doctors. Society as a whole has a very misguided view of M.E. and so the carer has to do all they can to keep this harmful ignorant tribal thinking from entering the world of the M.E. sufferer. They need to protect their healing space from influences, opinions and 'treatment' that will cause disease progression and maybe even death.
But who protects the carer?

In some ways the carer is as vulnerable as their loved one."

".....the carer is as vulnerable as their loved one....."

That says it all about ME

And Lili?

"Lili collapsed after her last hospital visit.
She passed out with a seizure, her body violently shook, and paralysis spread throughout her body.
It was an extreme reaction to the overload of physical, cognitive and sensory attack on her body during that year, but this last journey to the hospital was the straw upon the last straw that broke her body down.
She never recovered."

Disability and Human Rights

ME is not alone in being an easy target for the DWP to unleash its draconian and ideologically driven policy assault on disabled people.

Yet no other disease has had funding from the DWP given to a research team to prove that simplistic therapies could be used to make patients better – or at least avoid them using funds from the public purse.

The PACE Trial had DWP funding included in the £5 million that was wasted to prove that Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET) were beneficial for "treating" ME.

The tale is rich in irony as it was due, predominantly, to the work of patients that the PACE trial was found to be flawed and totally unusable.

ME patients know well what it feels like to be at the sharp end of DWP coercion.

The current benefits system means that ME patients are likely to be judged by a third-party subcontractor who is totally clueless when it comes to knowing anything about the disease or its effects.

Of course, the DWP keep making the point that they judge on disability not on condition.

Yet how can a patient be judged fairly when the person judging them has no idea of the illness and how it affects the person attending the benefits review, either then or days after the interview?

The corporate parasites that DWP subcontracts to do the deeds presumably do not have to care about the effects on patients – they just carry out their instructions. Perhaps the DWP (which is effectively the government of the day) and the ministers who decide DWP policies feel cleaner, less soiled this way - yet continually forget that they are servants of the public.

The DWP were actually found to have a target of 80% to refuse mandatory reconsideration requests as a Key Performance indicator.

Both government contractors have previously been found to have bungled disability tests.

Invest in ME Research were long ago told by an ex-member of the DWP fraud team that the actual fraudulent element from benefits was less than 3% and the official government figures for fraud now are far less.

The Press Association revealed in 2017 that Atos and Capita were set to be paid more than £700 million for their five-year contracts

One is left to wonder if these external profit centres are really required, especially when so many appeals against denial of benefits are eventually won. What of the effect on society?

The whole benefits system for disabled people – including ME patients – is in disarray and produces an anxiety-ridden exercise which may further exacerbate a patient's condition. Universal Credit rollout has turned into an exercise in incompetence.

And some charities cannot complain as they take money from the government and are under contract not to criticise.

In a recent article, "Britain's most senior tribunal judge says most of the benefits cases that reach court are based on bad decisions where the Department for Work and Pensions has no case at all.

Sir Ernest Ryder, senior president of tribunals, also said the quality of evidence provided by the DWP is so poor it would be "wholly inadmissible" in any other court."

And the effects were expertly captured by this tweet from a doctor -

Professor Tom Shakespeare at University of East Anglia has researched and published work on the biophysical explanation for disabilities and how benefit awards have arisen from the Waddell-Aylward model.

In his preface to book Science, Politics,.....and ME, by Dr Ian Gibson and Elaine Sherriffs, Professor Shakespeare wrote the following –
"Rather than judging whether a person has a practical chance of being able to find a job they can do in the actual labour market, the Work Capability Assessment investigates whether the person has the ability, in theory, to do any form of work at all, thus tightening the eligibility criteria substantially and making it more difficult to qualify for Employment Support Allowance."
Another change has been introduced, as he says:
"A second change is that instead of using a person's regular GP, who knows them and their difficulties, an 'independent assessor' is used, who does not necessarily understand how illness or impairment impacts their life."
This can result again in the denial of benefits..."

The UK welfare system's' treatment of poor people (and that includes disabled people) in recent years has drawn attention from unlikely sources.
Philip Alston, "the UN's rapporteur on extreme poverty and human rights, warned that poverty in the UK is a "political choice" and that compassion and concern had been "outsourced" in favour of tax cuts for the rich.".

Of course all of these things overlap when we discuss ME – all interplay – and one can imagine it is all part of the grand establishment strategy.
The benefits scandal that denies disabled people what they deserve by using non-medical subcontractors to assess people;
where targets are set to deny benefits and make patients undergo unnecessary duress to overcome a pre-conceived outcome for their disability assessment;
where the DWP fund research aimed solely at proving ME can be "fixed" by simplistic approaches that fund careers and assist insurance companies;
where the official flawed guidelines are rigidly decided by an institute that claims to be responsible for clinical excellence yet seems to ignore patients' experiences and aligns more with the BPS lobby;
where insurance companies deny benefits to patients if they choose not to try the recommendations in the flawed official guidelines that propose harmful therapies such as CBT and GET as treatments;
and the possible payment of government funds to charities to avoid criticism by buying their silence.
Played out using ME patients as the pawns.
Quod erat demonstrandum

World Human Rights Day, like many grand ideas, has a noble purpose.
Yet despite their profound messages and campaigns the basic rights to health of ME patients are continually infringed and discarded. Lip service only is paid to the world quangos such as WHO and UN by governments and establishment organisations. For ME there is never any follow up on the implementation.

Where was the UN when poor ME patient Karina Hansen was incarcerated in Denmark?
Who covered the human rights of Sophia Mirza when she was forcibly sectioned?
Where have the Governments, DoH, CMO, NICE been in protecting human rights?
Who are they serving?

Can one think of another case where it is so detrimental to patients when one doctrine is forcibly imposed on vulnerable people by establishment forces against common sense and when there is no evidence base that stands up to proper scientific scrutiny?

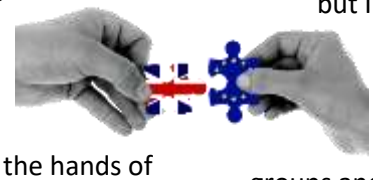
From the charity's' response to the 2007 NICE Draft guidelines we have reused the comments on human rights provided by R. Mitchell and V.Mitchell.

Private Health Insurers cannot force an M.E. client to undergo unwanted treatment before making a payment, unless those treatments are specified in the contract.
Unless the contract of a company states clearly that M.E. clients must undergo CBT and/or graded exercise before a payment is made, the company could well be in breach of contract. Also, every individual has freedom to express views as stated by

The Human Rights Act 1998. If an insurance company ignores a client's reasons for refusing CBT and/or graded exercise, a client could claim their 'freedom of expression' has been violated.2

The Human Rights Act 1998, European Convention for the Protection of Human Rights and Fundamental Freedoms, Section 1, Article 10, no.1 The guidelines should have had a significant increase in evidence-based assessment and treatments beyond the psychosocial model and CBT/GET treatments before it can be accepted as an independent, expert guideline for the treatment of ME/CFS.

In 2007 the recommendation from NICE to use psychological therapies for treating ME contravened the human rights of patients.
It was stated that by ignoring the serious issues with regard to CBT and GET the NICE guidelines would violate the right of clinicians and patients to the highest, safest standards of medical practice and care, amounting to a violation of their Human Rights, apart from major concerns about the efficacy of use of CBT or about the danger in the use of GET.
There was no regulatory framework governing the development and use of CBT and GET thus leaving ME patients vulnerable to exploitation and abuse at the hands of the vagaries of power, politics and prejudice (which has been proven correct).
In respect of informed consent for using these therapies the issue did not arise as there simply cannot be informed consent since there are important ethical, safety and regulatory questions arising from these treatments, to be addressed.



It was hard to envisage any Independent authority clearing a drug for Human testing or use without ethical and safety issues, like those surrounding Psychological Therapy, being resolved.

By ignoring these serious issues with regard to psychological therapy the NICE guidelines violated the right of clinicians and patients to the highest, safest standards of Medical practice and care, amounting to a violation of their Human Rights. This was a Human Rights issue.

And what of today when one sees NICE retaining these harmful therapies as recommendations for treatment for ME despite being told they are harmful?

ME and the EU

What has been causing billions of pounds of damage to the economies of Europe, and affects the lives of hundreds of thousands of people?

Yes, ME - of course.
However, rivalling it in recent years has been Brexit.

Brexit may mean Brexit for some – but leaving the EU does nothing to help patients with ME.
Research itself suffers due to the lack of EU funding available and UK researchers will be excluded from leading EU projects.
We have already seen examples of how this is affecting research plans.

We were hoping that one advantage of Brexit, at least for the remaining EU countries, was that other European healthcare systems would no longer pay any attention to UK's NICE and its flawed guidelines for ME.
Instead new policies could be formed.

We may be being led headlong into the Brexit abyss but IiMER does not intend to break links with Europe.
IiMER is part of the European ME Alliance (EMEA), now fifteen countries working together on ME and including groups and advocates with the same objectives.
EMEA is a member of the European Federation of Neurological Associations (EFNA), with a member on the board representing ME, and works together to improve recognition of ME within Europe.

What is clear is that the same problems that exist with ME in the UK also exist, to a greater or lesser extent, in all other European countries.

One of IiMER's great supporters – Mike Harley – is running 28 EU marathons to support the charity in raising awareness and developing a Centre of

Excellence for ME that can perform translational biomedical research in a European hub, able to develop treatments for ME.
Apart from raising funds and enormous awareness of ME Mike has also been able to look at issues in each European country.
His blog not only details his marathon events. He has also made an effort to report on the situation with ME around Europe by discussing with ME patients in the country in which he is running.
And it is very illuminating.

Different countries, but all sharing the same problems.
Politics, the influence of Biopsychosocial (BPS) doctrine, the lack of funding for proper research, recommendations from official bodies for deleterious Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET), the lack of belief of doctors in the disease, the stigma and mistreatment around ME, patients having to research themselves, the problem not being dealt with and not going away.....

Let us look at some of the comments that Mike brought back from patients in the countries in which he ran.

DENMARK

“Very few doctors in Denmark know that ME is a biological illness, so most patients do not get an ME diagnosis.”
"Instead, when a patient presents with ME symptoms, they are told that they are stressed, just need to pull themselves together and get some exercise. “
“The main reason for this overwhelmingly negative attitude about ME, is a long campaign by a group of psychiatrists who are working to have ME seen as a form of somatoform disorder"

AUSTRIA

"A doctor in Vienna, recommended to me by a ME / CFS group, made a diagnosis of CFS, amongst other things. I cannot obtain a second opinion, because according to ME / CFS Help Austria, this doctor is the only one in Vienna!"

“…hardly anyone takes you seriously, you are usually left totally alone, especially by doctors, you are ridiculed, accused of just being lazy, not wanting to get better, and told that you should just make more of an effort. !”

MALTA

"There is no study or any estimates to show or at least a demarcation if there ever was any study to establish a percentage of how many ME sufferers there are there. Some doctors say it is approx. 0.02 % same as in Europe. Due to unwillingness to diagnose and lack of knowledge on ME, it's difficult for doctors to give an accurate figure."

SLOVENIA

"They don't support us too much around this disease, like we're nothing. We are not noticed even though we are very tired and we are hurting. We are invisibly ill, like a house that has a nice facade, but you can’t see that inside it has a fallen staircase and a broken sink."

NETHERLANDS

“I was denied help for cleaning as it was considered anti rehabilitive and a house because a psychologist told me that he didn't see anything wrong with me or my situation. Financial support went well but for many it's very difficult, more often than not people even need to fight it out in court. Very sad”.

FINLAND

"CFS/ME is classified as a psychiatric disorder by most of the doctors and they tend to treat it with antidepressants and graded exercise therapy (GET) which are potentially very harmful to patients and may permanently worsen their condition. Fortunately for the patients even these harmful therapies seem unavailable as there are no experts even to carry out GET-therapy. Patients are totally left without any care."

IRELAND

"Our own Department of Health tends to follow the advice given by the UK Department of Health.

Following the 2002 CMO report in the UK, our then Chief Medical Officer told an IMET delegation that they wouldn't intend to reinvent the wheel, but would follow the course laid down by the UK."

GREECE

"As far as the Government is concerned, it doesn't have a clue about ME/CFS
Greece does not have a specialist clinic for the diagnosis and treatment of ME/CFS"

SWEDEN

"..the psychosocial view is common, and there is a disturbing tendency to clump ME/CFS together with medically unexplained symptoms (MUS). However, there are a minority of doctors who recognise ME/CFS as a biomedical illness."

POLAND

"In Poland, the illness is largely perceived as being in the mind and not a biomedical condition. there is one center in Bydgoszcz where ME is diagnosed, but they then tell people to exercise"

BELGIUM

"ME is being perceived as a psychological disorder treated with CBT and GET despite the fact that the KCE (Federal Knowledge Centre for Health) issued a report in 2008 stating that this therapy given in the reference centres, wasn't effective
Getting diagnosed in Belgium usually takes a lot of time. With the available care facilities being ineffective and insufficient, patients with CFS have to wait sometimes years to receive a diagnosis."

FRANCE

"Support for ME/CFS patients in France is still very uncertain and often very difficult to obtain. Despite suffering very severely patients often find that their disability is not recognised, and this adds to their suffering."

SPAIN

"I think we could count the doctors willing to be updated at the international level with the fingers of a hand
I've seen/read many other experts in the country say things that are completely out of tune with the international conception of the illness. lot of doctors have laughed at me when I told them I had CFS, others have told me I just needed to get a boyfriend... "

LITHUANIA

"Some doctors want to get rid of you as quick as possible, because your results are good. They think you are pretending or something. ..... I don't think the government care, because this illness is invisible and there is not enough proof that it's real."

CZECH REPUBLIC

"No diagnostic and therapeutic standards for ME / CFS have been introduced into clinical practice in the Czech Republic. Patient care depends on their luck whether they can find a doctor who does not solve whether or not he is diagnosed (and does not send everyone to psychiatry immediately), but he is treating real problems."

We know that the evil of BPS has been allowed to spread its insidious network throughout Europe – like a cancer through each health system, corrupting doctors and research councils everywhere.
At a time where the mess of Brexit seems like a microcosm of the unpredictability and the unravelling of the world today then one thing is certain – IiMER will still stay close to Europe via EMEA and other initiatives such as the European ME Clinicans Council (EMECC) concept.

Leaving the EU will make no difference to the actual fact that, in all of the different EU countries, the problems with ME are the same as in the UK and will require the same efforts to be made to force change.
Mike's EU marathon reports are here - **http://www.mikeseumarathons.eu/me-in-the-eu.html**

Children with ME

"There is clear evidence of the impact of ME/CFS on the education and social development of these young people. The stigma and social effects of pediatric ME/CFS include the loss of normal childhood activities and in some extreme instances, inappropriate forcible separation of children from their parents"
- Institute of Medicine (IOM) Report - "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness" February 2015

For any parent the event of their child being diagnosed with a disease is one of the worst of experiences that they will ever have.

To then discover that there is no treatment, let alone a prospect for any cure, will likely make them search for the reason(s) why - expecting to find answers, but instead finding more questions.

To realise that this disease is ignored by governments, restricted from any level approaching adequate funding by research councils, treated inappropriately by institutes supposedly responsible for excellence in care, and used as a means to build careers and support egos for others – all this makes it even more incomprehensible.

To learn that a powerful and influential lobby has been largely responsible for maintaining the above and even influencing the establishment policies and the media portrayal of this disease as a condition that can be changed just by trying harder or thinking differently – then the nightmare turns into a continuous horror.
For children, of course, the future is often upended - with possible additional consequences caused by the disease, apart from the direct symptoms from the condition itself.

Losing school, losing contact to friends, losing any social life - isolation.
Could it get any worse?

In the UK yes!
A child may be branded with the scandalously contrived soundbite of Pervasive Refusal Syndrome or some other such nonsensical catchphrase?

Yet, despite this surreal and sometimes ugly scenario, we see many examples of the resilience and courage of children with ME - young people who deal with the effects of ME on their health and their lives and yet continue to hope and believe in a better future.
The great majority remain positive and maintain an unbelievable lack of any resentment for their situation - blaming nobody, stoically handling this disease . Quite remarkable.

We have many examples also of young people supporting the charity and using what possibilities they have to raise awareness and funds.
Some take action themselves.

Last summer we received this image from Professor Kristian Sommerfelt in Norway - a drawing by young Emma who so clearly explained in her image here what ME is like for a young person.

In the UK an estimated 25,000 children have ME - but nobody knows for sure as data is not currently collected!
There are so few paediatricians that understand ME - another failure of establishment policies.

Even those who are qualified, knowledgeable and appreciated by parents of children with ME are given a hard time – see http://www.investinme.org/IIME-Newslet-1604-NS999.shtml

As for paediatric research - well, the less said about that the better.
We have commented before on the appalling SMILE trial and on pyramid businesses that are unregulated, unaccountable and unscientific. Junk research that attracts funding thanks to a rigid system that defies any logic or concern for children.

Removing isolation

Most of the effort from Invest in ME Research in recent years has been aimed at trying to get research into ME started that looked at the long term. However, we have also looked at other issues – the consequences of ME.
One insidious consequence is isolation – affecting young and old patients. Little had been done to tackle this. This year we wanted to change how young people may be affected by this.

A disease such as ME presents many challenges to a patient and to a family. It can provide challenges also to schools when a child or young person is unable to continue full time education.
In such situations families can find themselves on the receiving end of the ignorance about ME that pervades our society where social services and education authorities may use a one-size-fits-all attitude to treating families where the child must remain at home.

Children and youths with long-term illness such as ME do not need to be excluded from their friends' activities and progress and schools have a responsibility not to ignore them – something which can otherwise lead to long term discrimination.

We started a trial of remote participation by working with Norwegian company No Isolation to conduct a trial for young people with ME and the results were very good.
This trial not only facilitated the re-connection of young ME patients to their schools.
It also recreated the social relationships.
We feel that it also educated other children – and their families, and teachers and possibly SENCOs.

No Isolation & Invest in ME Research

No Isolation is a Norwegian-born start up founded with the aim of reducing loneliness and involuntary social isolation through the creation and implementation of warm technology. Its first product is a physical avatar named AV1, which allows children and young adults, who are forced by illness to take extended time away from school, to maintain a presence in the classroom and communicate with friends.
In 2017, to expand the number of children it could help, No Isolation launched in the UK, and today, over 900 children use AV1 across Europe. While in the Nordics, AV1 was largely used by children suffering from leukaemia; however, since its arrival in the UK, AV1 has fast become an invaluable lifeline for children with Myalgic Encephalomyelitis (ME) thanks to Invest in ME Research.

One of the UK's most avid users is 15-year-old Makayla Nunn, who was first diagnosed with ME aged eight. Makayla was introduced to the technology through the trial arranged by Invest in ME Research. Her family and school saw how essential AV1 had become to help Makayla maintain the increased attendance in class, and subsequent increase in grades and social confidence. Makayla has been using her AV1, who is lovingly named Robbie, for well over a year now.

There is no better way to explore the AV1's success in transforming the life of someone with ME, than to speak with a real-life user. Ahead of this year's Invest in ME Research conference, we caught up with Makayla and her mother about their experiences with the technology.

Hi Makayla, can you tell us a little bit about your journey with ME?

I was diagnosed with ME at eight years old, and since then I have been unable to attend school full time due to tiredness, flu-like symptoms, and brain fog. I also suffer from hyper-mobility syndrome, meaning that it often hurts to move my joints, and POTs (postural orthostatic tachycardia), which causes a spike in my heart rate, leading to dizziness and fainting. As well as missing out on school, I had to give up sports and hobbies, including dancing and

swimming. I can't horse ride as much as want to, either.

When did you first encounter AV1?

I saw on the news that Jade Gadd had used a robot called Bee (her AV1) to assist her with a different condition, then Invest in ME Research asked me if I would like to try an AV1 out for three months. As I was behind at school, my mum and I thought that the robot could help me attend extra hours of school from home, taking the pressure off my education. I got my AV1 in January 2018, and now, Robbie is part of the family!

How did your class react to having AV1 in the classroom?

It was quite strange at first. Robbie used to get a lot of attention from my class when we were attending the lesson. My class really like him being there, it was the school that named him, and one of the staff members even made Robbie a cape to keep him warm when he's going between buildings!

How has AV1 helped you better cope with your condition?

If I am having a day where I am feeling very tired or ill, I often don't feel up to going into school. With Robbie, I can now work from home on these days, rather than having to miss out entirely. This helps me hugely, because to do this, I don't have to physically push myself too much, which can make me feel worse.
Using Robbie is just like being in class, because when I need to get my teacher's attention I can light up Robbie's head, just like putting a hand up. I can also put the 'sleep mode' on if I want to be in the lesson but don't feel up to saying too much.

Do you think that your AV1 will give you more opportunities for the future?

I'm not as behind in school any more, my grades have improved and I feel more confident. This is good because exam work has started for my GCSE's, so Robbie is helping me to catch up on the stuff that I have missed previously, having been on reduced hours of school for the last 7 years.

We were also lucky enough to catch up with Makayla's mother, Michelle, too.

Hi Michelle, how has AV1 changed family life?

AV1 has made me more confident about Makayla's education. When she is struggling at school she gets frustrated and upset; falling behind the rest of the class. By giving her the ability to attend more lessons through Robbie, it gives her more control, which is a massive boost for Makayla.

How has AV1 changed Makayla's education?

Robbie has helped Makayla beyond my expectations! When she's having a bad day she knows she's not under pressure to go in anymore, because we can send Robbie in. This has taken a lot of pressure off her and having Robbie as a safety net has made the world of difference. She's not forcing herself to go to school on days when she needs to rest, which in turn makes her worse in the long run. In a way, Robbie is helping her overall health.

How has AV1 changed Makayla's daily life?

As a parent, I am always being told 'you should limit this' or 'Makayla can't do that'. Robbie has really helped to take the 'you can't' away. Robbie has given hope to other children and parents too, as most with ME have had to drop out of education. Aside from education, Robbie helps Makayla see her grandmother. When illness has prevented Makayla visiting her grandmother (for the worry of contagion), a remote visit through AV1 can help Makayla and her grandmother spend more time together.
What do you hope for the future?
We are hoping technologies like the AV1 will change people's attitudes towards ME. Clarifying that the illness is not about people not wanting to do things, but it is about them not wanting to be sick. They have had to give up so much. This is a real illness that affects so much more than just their health - it affects life. I've been so surprised at how well Robbie has supported Makayla. Allowing her to carry on with her education has made Makayla far more confident. It has also given Makayla had one less thing to worry about: the isolation that she felt and the awkwardness of feeling left behind.

The Anne Örtegren Memorial Lecture 2019

Anne Ortegren - A Year On

It is a year since news came of the passing of Anne Örtegren.

The lives of those who have passed away are placed in the memory of the living. A year passes and the shock of the news of Anne's death may have ebbed away somewhat - yet the void remains, covered by the memory of one woman whose courage, dignity and influence were evident always - and continue to inspire.

Reading Anne's **Last Post** - an articulate, reasoned and eloquent article that gives insight into the loss of this amazing person - it may seem that she was recounting the situation that she found herself in and reasons for her course of action.

That, itself, would have been an enormous effort. Yet, with Anne, this article was also likely to have been written to help so many others in the future - so typical of Anne's selfless actions.

In her last post Anne wrote –

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

- You need to bring funding for biomedical ME/CFS research up so it's on par with comparable diseases (as an example, in the US that would mean $188 million per year).
- 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/CFS 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/CFS patients a future."

A year on. We would have liked to have written that things have changed, that a new path is opened, that Anne's experiences will never have to be repeated. We cannot state this.

Our status report from summer of 2018, prior to the UK parliamentary debate on ME, highlighted a picture of wasted lives and wasted opportunities over these many years where little has changed, thanks to establishment apathy.

Yet we remain hopeful of change coming - albeit far too slowly.

Therefore, the charity is developing a new initiative that will build on Anne's influence and may, in some way, honour her memory.

We will continue to arrange for the **Anne Örtegren Memorial Lecture** to be given at our annual international ME conference in.

In memory of Anne we released the tribute to her from last year's IIMEC13 conference DVD that occurred prior to the inaugural Anne Ortegren Memorial Lecture. Here, quite appropriately, a distinguished Swedish scientist – Professor Jonas Blomberg – spoke of Anne.

Little did we know then that a year later we would be mourning the sad loss of Professor Blomberg himself.

As we wrote last year - when we lose a friend we lose a part of ourselves.

Anne's influence on the lives of others lives on.

http://investinme.org/AnneOrtegren.shtml

Conference Abstracts

Dr Ian Gibson
Former Dean of Biological Sciences, UEA

Dr Ian Gibson, former Labour MP for Norwich North, worked at University of East Anglia for 32 years, became Dean of the school of biological sciences in 1991 and was head of a cancer research team and set up the Francesca Gunn Leukaemia Laboratory at UEA. In 2011 Dr Gibson received an honorary doctorate of civil law from UEA.

Professor Markku Partinen
University of Helsinki, Finland

Prof Markku Partinen is a neurologist and an internationally well-known opinion leader and expert in sleep research and sleep medicine.
Professor Partinen is currently Director of the Helsinki Sleep Clinic, Vitalmed Research Centre, and Principal Investigator of Sleep Research at Institute of Clinical Medicine, Clinicum, University of Helsinki, Finland. He has been the coordinator of the NARPANord Narcolepsy Consortium.
He has published more than 330 original articles in peer reviewed Journals in addition to writing many book Chapters and editing several books.
He has been President of the ESRS congress in 1992 (Helsinki), the World Congress of Sleep Apnea in 2003 (Helsinki), and the WASM congress in 2007 (Bangkok).
Currently he is a Member of the Board in the ESRS EU-Narcolepsy Network (EU-NN) and Chair of Scientific Board of the EU-NN, President of the Finnish Parkinson Association and President of the Finnish Sleep Research Society.

Professor James Baraniuk
Professor of Medicine at Georgetown University Medical Centre, Washington, USA

James N. Baraniuk was born in Alberta, Canada. He earned his honours degree in chemistry and microbiology, medical degree, and unique bachelor's degree in medicine (cardiology) at the University of Manitoba, Winnipeg,

Canada. Thereafter, he moved to Akron, OH, USA, for his internship and internal medicine residency at St Thomas Hospital. After another year of internal medicine residency at Duke University Medical Center, Durham, NC, he trained with Dr C.E. Buckley, III, in allergy and clinical immunology. He moved to the laboratory of Dr Michael Kaliner at the National Institute of Allergy and Infectious Diseases, Bethesda, MD, and there began his long-standing collaboration with Dr Kimihiro Ohkubo.

After 2 years studying neuropeptides, he joined Dr Peter Barnes' laboratory at the National Heart and Lung Institute, Brompton Hospital, London, UK. Dr Baraniuk returned to Washington, DC, and Georgetown University, where he is currently Associate Professor with Tenure in the Department of Medicine.

Dr Elizabeth R. Unger
Chief of Chronic Viral Diseases Branch, National Center for Emerging and Zoonotic Infectious Diseases, Division of High Consequence Pathogens and Pathology, Centers for Disease Control and Prevention

Elizabeth (Beth) Unger, PhD, MD, received an undergraduate degree in Chemistry at Lebanon Valley College, Annville, PA. She then earned her PhD and MD in the Division of Biologic Sciences at the University of Chicago where she also began a residency in pathology.

Her residency and fellowship was completed at Pennsylvania State University Medical Center. During this time, Dr. Unger developed a practical method of colorimetic in situ hybridization. This work led to interest in tissue localization of HPV and ultimately to her initial appointment to CDC in 1997 to pursue molecular pathology of HPV and CFS.
Dr. Unger has served as the Acting Chief of CVDB since January 2010 and has 13 years of experience in CVDB, where she has participated in the design and implementation of CFS research and HPV laboratory diagnostics. During this time, she was co-author on 25 peer-reviewed manuscripts related to CFS, including the often-cited descriptions of the Wichita and Georgia population-based studies. In addition, Dr. Unger has been instrumental in efforts by WHO to establish an HPV LabNet and serves as lead of a WHO HPV Global Reference Laboratory. She is co-author of 142 peer-reviewed publications and 24 book chapters and serves on the editorial board of six scientific journals. In 2008, for her HPV research accomplishments, she received the Health and Human Services (HHS) Career Achievement Award.

Dr Unger has been selected to serve as the Chief of the Chronic Viral Diseases Branch (CVDB) in the Division of High-Consequence Pathogens and Pathology (DHCPP), National Center for Emerging and Zoonotic Infectious Diseases (NCEZID), Centers for Disease Control and Prevention (CDC).

Dr Vicky Whittemore
Program Director in the National Institute of Neurological Disorders and Stroke at the National Institutes of Health in the United States.

Dr. Whittemore is a Program Director in the Synapses, Channels and Neural Circuits Cluster. Her interest is in understanding the underlying mechanisms of the epilepsies including the study of genetic and animal models of the epilepsies.
The major goal is to identify effective treatments for the epilepsies and to develop preventions.

Dr. Whittemore received a Ph.D. in anatomy from the University of Minnesota, followed by post-doctoral work at the University of California, Irvine, and a Fogarty Fellowship at the Karolinska Institute in Stockholm, Sweden.

She was on the faculty of the University of Miami School of Medicine in The Miami Project to Cure Paralysis prior to working with several non-profit organizations including the Tuberous Sclerosis Alliance, Genetic Alliance, Citizens United for Research in Epilepsy (CURE), and the National Coalition for Health Professional Education in Genetics (NCHPEG).

She also just completed a four-year term on the National Advisory Neurological Disorders and Stroke Council.

Professor Maureen Hanson Director, Center for Enervating Neuroimmune Disease. Liberty Hyde Bailey Professor, Department of Molecular Biology and Genetics, Cornell University, USA

Maureen Hanson is Liberty Hyde Bailey Professor in the Department of Molecular Biology and Genetics at Cornell University in Ithaca, NY. Previously she was on the faculty of the Department of Biology at the University of Virginia in Charlottesville and an NIH NRSA postdoctoral fellow at Harvard, where she also completed her Ph.D. degree. While most of her prior research has concerned cell and molecular biology in plant cells, she began a research program on ME/CFS after noting at a 2007 IACFS meeting the paucity of molecular biologists studying the illness. Her lab was part of the 2012 multicenter study organized by Ian Lipkin's group at Columbia University to assess the actual role of XMRV in ME/CFS.

Associate Professor Mady Hornig Associate Professor, Center for Infection and Immunity (CII), Columbia University Mailman School of Public Health New York, USA

Mady Hornig, MA, MD is a physician-scientist in the Center for Infection and Immunity (CII) at the Columbia University Mailman School of Public Health where she serves as Director of Translational Research and is an associate professor of epidemiology. Her research focuses on the role of microbial, immune, and toxic stimuli in the development of neuropsychiatric conditions, including autism, PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infection), mood disorders and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). She is widely known both for establishing animal models that identify how genes and maturational factors interact with environmental agents to lead to brain disorders and for her work clarifying the role of viruses, intestinal microflora and xenobiotics in autism and other neuropsychiatric illnesses that may be mediated by immune mechanisms. Under her direction, proteomic analyses of umbilical cord samples are identifying potential birth biomarkers for autism in a prospective study in Norway, the Autism Birth Cohort (ABC). She established that there was no association between intestinal measles virus transcripts and autism, and, with Brent Williams and W. Ian Lipkin at CII, has found altered expression of genes relating to carbohydrate metabolism and inflammatory pathways and differences in the bacteria harboured in the intestines of children with autism. She also leads projects examining the influence of immune molecules on brain development and function and their role in the genesis of schizophrenia, major depression, and cardiovascular disease comorbidity in adults, and directs the Chronic Fatigue initiative Pathogen Discovery and Pathogenesis Project at CII. In 2004, Dr. Hornig presented to the Institute of Medicine Immunization Safety Review Committee and testified twice before congressional subcommittees regarding the role of infections and toxins in autism pathogenesis. Her work in ME/CFS is establishing immune profiles and helping to identify pathogens that may be linked to disease.

Professor Don Staines The National Centre for Neuroimmunology and Emerging Diseases (NCNED), Griffiths University, Australia

Professor Staines has been a public health physician at Gold Coast Population Health Unit. He has worked in health services management and public health practice in Australia and overseas. His interests include collaborative health initiatives with other countries as well as cross-disciplinary initiatives within health. Communicable diseases as well as post infectious fatigue syndromes are his main research interests. A keen supporter of the Griffith University Medical School, he enjoys teaching and other opportunities to promote awareness of public health in the medical curriculum. He is now Co-Director at The National Centre for Neuroimmunology and Emerging Diseases (NCNED), Griffiths University in Australia

Abstract:

Role of transient receptor potential ion channels in the etiology and pathomechanism of ME/CFS

Staines D[1,2] Cabanas H[1,2,], Muraki K[2,3] , Balinas C[1,2], Eaton-Fitch N[,1,2], , Marshall-Gradisnik S[1, 2].
1.The National Centre for Neuroimmunology and Emerging Diseases, Menzies Health Institute Queensland, Griffith University, Gold Coast, Southport, QLD, 4222, Australia. h.cabanas@griffith.edu.au.
2. Consortium Health International for Myalgic Encephalomyelitis, National Centre for Neuroimmunology and Emerging Diseases, Griffith University, Gold Coast, QLD, Australia. h.cabanas@griffith.edu.au.
3. Laboratory of Cellular Pharmacology, School of Pharmacy, Aichi-Gakuin University, Chikusa, Nagoya, Japan.

NCNED has confirmed the pathology of transient receptor potential (TRP) ion channels in ME/CFS. TRP Melastatin 3 (TRPM3) impairment has been identified in three separate cohorts of patients. TRPM ion channels are non-selective calcium ion channels increasingly associated with systemic, particularly central nervous system (CNS), pathology. TRPM3 is highly concentrated in the CNS, (autonomic) ANS and (peripheral) PNS. The observed changes in gene structures and TRP receptor ion channel proteins are reflected in perturbations of intracellular calcium signalling. These findings have been demonstrated through electrophysiology patch-clamp technology, the gold standard for research into ion channel function. Drugs are now being analysed in this research context regarding suitability for pharmacotherapeutics and hence treatments.

The demonstrated pathology of TRPM correlates with symptom presentation in ME/CFS. Patch clamp identification of impaired TRP ion channels, the findings of drugs in a therapeutic context and the known roles of TRPM ion channels in systemic diseases establishes TRP pathology as the underlying cause of ME/CFS.
Additional data demonstrating changes in other TRP sub-family members is currently under publication. Whether these additional changes reflect compensatory mechanisms is being investigated.

Dr Jesper Mehlsen
Bispebjerg Hospital, Copenhagen, Denmark

Jesper Mehlsen graduated as a doctor in 1979 from the University of Copenhagen and became a specialist in 1990. For 35 years he has been working clinically and in research with patients with disorders of blood pressure control, with dizziness, fainting (syncope) and near-fainting in upright position. He is author / co-author of more than 140 articles in international journals and has been the leader of a number of research projects in these fields and with projects related to HPV vaccination.

Over the past 5 years, he has performed clinical research with patients who suspect vaccine damage as the cause of the development of a number of symptoms that are often common to those seen in chronic fatigue syndrome / ME.

His expertise is in Autonomic nervous system, Heart rate and blood pressure control, Cardiovascular physiology and pathophysiology, HPV vaccines and -complications
His Main research areas relate to methods for the study of autonomic cardiovascular control; Mathematical modelling of cardiovascular control; Autoimmune response to vaccination; Mathematical modeling of the neuroinflammatory reflex.

His current research involves mathematical analysis of hemodynamic adaptations to the upright posture; mathematical analysis of hemodynamic response to Valsalva manoeuvre; dynamic T-wave alterations and the autonomic nervous system; mathematical analysis of cytokine response to LPS in humans; autoimmunity in patients with possible side effects to HPV vaccination.

He places great emphasis on taking time to listen, investigate, explain and find treatment options based on a holistic assessment and in close interaction with the patient

Dr Øystein Fluge
Haukeland University Hospital, Bergen, Norway

Oystein Fluge received medical degree in 1988 at the University of Bergen, and is a specialist in oncology since 2004. He has worked as a Research Fellow with support from the Norwegian Cancer Society and is now chief physician at the Cancer Department, Haukeland University Hospital. Doctoral work emanates from the Surgical Institute and Department of Molecular Biology, University of Bergen.

Professor Stuart Bevan
Professor of Pharmacology at the Wolfson Centre for Age Related Diseases, Kings College London, UK

Professor Stuart Bevan is Professor of Pharmacology at the Wolfson Centre for Age Related Diseases. From 1997 to 2005, he was Head of the Chronic Pain Unit for Novartis based in the Novartis Institute for Biomedical Research laboratories on the UCL campus.

Our studies are focused on sensory transduction in neuronal and non-neuronal cells, the transduction and transmission of noxious and innocuous stimuli in peripheral sensory nerves and mechanisms of pain and analgesia. These investigations are carried out using a combination of in vitro and in vivo approaches.

Transient receptor potential (TRP) channels
Much of our current research involves studies on TRP Channels. TRP channels have diverse roles in sensory transduction and cellular regulation. We have a specific interest in TRP channels expressed by peripheral sensory neurons and interacting cells such as keratinocytes as well as non-neuronal cells in the gastro-intestinal tract. Several of these channels are important sensors of thermal stimuli. For example, TRPV1 is activated by noxious high temperature (>42°C), TRPM8 by cool temperatures (<~28°C) and TRPV3 by warm temperatures (>32°C). TRPA1 can also be activated by noxious cold temperatures. TRPV1 and TRPA1 are expressed by sensory nerves that respond to noxious stimuli and these two channels are also sensitive to pungent chemicals such as capsaicin found in chilli peppers (TRPV1) and allyl isothiocyanate found in mustard and wasabi (TRPA1).

His interest is to determine the roles of TRP channels and other ion channels and receptors in normal physiology and in disease states. The activities of channels and receptors are studied using electrophysiological measurements from native cells (such as sensory neurons) and cells heterologously expressing molecules of interest.

Professor Simon Carding
Research Leader, Quadram Institute Bioscience

Upon completing postgraduate work at the Medical Research Council's Clinical Research Centre in Harrow, Simon Carding took up a postdoctoral position at New York University School of Medicine, USA,and then at Yale University as a Howard Hughes Fellow in the Immunobiology Group at Yale University with Profs Kim Bottomly and Charlie Janeway Jr. While at Yale an interest in gamma-delta (γδ) T cells was acquired working closely with Adrian Hayday on molecular genetics and then with Prof. Peter Doherty to establish their role in (viral) infectious disease. He left Yale after five years to take up a faculty position at the University of Pennsylvania in Philadelphia where he developed a research interest in mucosal and GI-tract immunology, performing studies in germfree mice with Prof John Cebra that helped establish the role of gut microbes in the aetiology of inflammatory bowel disease (IBD).

After 15 years in the USA, he returned to the UK to take up the Chair in Molecular Immunology at the University of Leeds where he established a new research programme on commensal gut bacteria and Bacteroides genetics leading to the development of a Bacteroides drug delivery platform that is being used for developing new interventions for IBD and for mucosal vaccination.

In 2008 he was recruited by UEA and IFR to develop a gut research programme, taking up the Chair of Mucosal Immunology at UEA-MED and the position of head of the Gut Biology Research Programme at IFR, which later became part of the Gut Health and Food Safety (GHFS) Programme. GHFS research covers a broad area of gut biology including epithelial cell physiology, mucus and glycobiology, mucosal immunology, commensal microbiology, foodborne bacterial pathogens, and mathematical modelling and bioinformatics. The success of this programme has led to the establishment of the Gut Microbes and Health research programme that is integral to the research agenda of The Quadram Institute.

Within these programmes, much of the work undertaken in his research group builds upon that carried out in the USA and latterly in the UK with a major focus on understanding the mechanisms of intestinal microbial (bacterial and viral) tolerance. In particular, identifying the pathways and mediators of microbe-host cross talk and the role they play in establishing and maintaining gut health and in diseases that not only affect the gut but other organ systems. This has led to the development of new research projects relating to the gut-microbiome-brain axis and understanding how the intestinal microbiome impacts on mental health and the development of neurodegenerative diseases, and the intestinal virome and the role that prokaryotic and eukaryotic viruses play in microbial homeostasis and dysbiosis.

Professor Karl Johan Tronstad Professor Institute for Biomedicine , Tronstad Lab, Bergen, Norway

Prof. Tronstad completed his graduate studies in biochemistry at the University of Bergen (UiB) in 2002. As postdoc at the Haukeland University Hospital, he studied bioactive compounds with the potential to modulate mitochondrial functions in cancer cells. In 2005 he was recruited to the Department of Biomedicine, UiB, where he started his research group to investigate metabolism and mitochondrial physiology. His laboratory seeks to better our understanding of how defective mitochondrial homeostasis may disturb cell physiology, and how this may be involved in mechanisms of cancer and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).

Karl was involved with the recent paper to come from Bergen - Journal of Clinical Investigation Insight. The Tronstad Lab investigates cell metabolism and mitochondrial biology and we are very fortunate that he can spare time to participate in the Colloquium.

Professor Nancy Klimas, Director, Institute for Neuro Immune Medicine, Nova Southeastern University USA

Nancy Klimas, MD, has more than 30 years of professional experience and has achieved international recognition for her research and clinical efforts in multi-symptom disorders, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Gulf War Illness (GWI), Fibromyalgia, and other Neuro Immune Disorders. She is immediate past president of the International Association for CFS and ME (IACFS/ME), a professional organization of clinicians and investigators, and is also a member of the VA Research Advisory Committee for GWI, the NIH P2P CFS Committee, and the Institute of Medicine ME/CFS Review Panel. Dr. Klimas has advised three Secretaries of Health and Human Services, including Kathleen Sabelius, during her repeated service on the Health and Human Services CFS Advisory Committee. Dr. Klimas has been featured on Good Morning America, in USA Today and the New York Times.

Dr Ron Tompkins Director of the Center for Surgery, Science and Bioengineering, Massachusetts General Hospital, USA

Ronald G. Tompkins, MD, ScD, is the Sumner M. Redstone Professor of Surgery at Harvard Medical School, Founding Director of the Center for Surgery, Science & Bioengineering at Massachusetts General Hospital, and Chief of Staff Emeritus at Shriners Hospitals for Children—Boston.

The Center, a division of Surgery at Mass General, is a newly established center for research and innovation based upon the Mass General Burns Division's collaborative track record and expertise in securing more than $200 million in federal, foundation, and industrial support for basic research and clinical programs.
It is a clinically-driven enterprise that engages in the basic sciences and engineering to solve everyday challenges in clinical medicine. The center promotes the development of new approaches to healthcare delivery and personalized medicine, minimally invasive therapies, as well as a myriad of new technologies such as re-engineered organs, smart nano-pharmaceuticals and nano-diagnostics, and living cell-based microfabricated devices for diagnostics, therapeutics, high-throughput drug screening, and basic and applied biomedical investigation.
He is a board-certified general surgeon with a doctorate in chemical engineering, which provides him with expertise not only in the clinical evaluation of critical care patients, but also in inflammation biology, genomics, proteomics, and computational biology.
Elected as a Director of the American Board of Surgery in 1994, he has received multiple honors including a fellowship from the American Institute for Medical and Biological Engineering and an honorary M.A. from Harvard University. He has served as an officer including as President and Board Member of more than a dozen national and international academic societies.
Dr. Tompkins has published more than 450 research papers in medicine and engineering journals and has contributed to the advancement of science and engineering through service on institutional advisory panels, moderating mini-symposia and workshops on biotechnology, and studying the genomics and proteomics of immunology and metabolism resulting from injury.
Together with his Division colleagues, nearly 300 fellows have been mentored in the Division's training programs with many excellent success stories.

Professor Michael VanElzakker
Massachusetts General Hospital/Tufts University, USA

Dr. VanElzakker received a master's degree in behavioral neuroscience at the University of Colorado, working in Dr. Robert Spencer's neuroendocrinology laboratory, and a PhD in experimental clinical psychology at Tufts University, working in Dr. Lisa Shin's psychopathology neuroimaging laboratory. His postdoctoral fellowship is at Massachusetts General Hospital/ Harvard Medical School, at the Martinos Center for Biomedical Imaging, in the Division of Neurotherapeutics.

Dr. VanElzakker is interested in uncovering the mechanisms of post-traumatic stress disorder (PTSD), and of myalgic encephalomyelitis - also known as chronic fatigue syndrome (ME/CFS).

His PTSD research uses functional and structural brain imaging, behavioral attention tasks, blood, and genetic data to investigate what makes some individuals vulnerable to PTSD following trauma. He is interested in using non-invasive electroceutical medical devices to enhance safety learning, which may eventually serve as an adjunct to enhance exposure-based therapy for PTSD.

His ME/CFS research uses functional and structural brain imaging to look for abnormal patterns in brain metabolism and inflammation in this patient population. This research focuses on dysfunction at the intersection of the nervous and immune systems and posits that ME/CFS may be what happens when the nervous system detects an exaggerated and ongoing innate immune response. He is interested in using non-invasive electroceutical medical devices to enhance the anti-inflammatory vagus nerve reflex.

Professor Ron Davis
Professor of Biochemistry and Genetics at the Stanford School of Medicine in Stanford, California, USA

Ronald W. Davis, Ph.D., is a Professor of Biochemistry and Genetics at the Stanford School of Medicine in Stanford, California.

He is a world leader in the development of biotechnology, especially the development of recombinant DNA and genomic methodologies and their application to biological systems.
At Stanford University, where he is Director of the Stanford Genome Technology Center, Dr. Davis

focuses on the interface of nano-fabricated solid state devices and biological systems.
He and his research team also develop novel technologies for the genetic, genomic, and molecular analysis of a wide range of model organisms as well as humans.
The team's focus on practical application of these technologies is setting the standard for clinical genomics.
The genomic revolution has been spurred by technological advances that made nucleotide sequencing inexpensive, high-throughput, and accessible. The next phase in this revolution to pave the way for personalized health entails similar breakthroughs in biosensor technologies for personal molecular monitoring. Just as with DNA sequencing, the key features to optimize are accuracy, sensitivity, cost, and accessibility. Through close collaboration between engineers, biochemists, geneticists, and clinicians, our team has developed several such technologies and devices. The technologies target the biophysical properties of the cells and molecules, and therefore do not rely on introducing labels or other complex sample preparation techniques. We have successfully applied these technologies to detecting drug resistance, resolving cells and molecules in bodily fluids and tissues, and engineering advanced, multiparametric, wearable biosensors. We have begun applying these methods to understand chronic fatigue syndrome, one of the last major diseases about which almost nothing is known. We anticipate that these technological breakthroughs coupled with data integration of personal molecular profiles will play an instrumental role in the realization of personalized health regimens and disease prevention strategies.

IIMEC14 AGENDA

Start	Presentation	Presenter
07.45	*Registration*	
08.45	IiMER	Opening
09:00	#InvestinMEResearch	Dr Ian Gibson
09:10	CDC update	Dr Elizabeth Unger
09:25	NIH Update	Dr Vicky Whittemore
09:45	Immune Dysregulation in ME/CFS	Professor Maureen Hanson
10.10	Fingerprinting the Phenotypes of ME/CFS Along the Gut-Immune-Brain Axis	Assoc. Professor Mady Hornig
10:35	Refreshments Break	
11:05	Transient receptor potential ion channels in the aetiology and pathomechanism of CFS/ME	Professor Don Staines
11:30	Pathophysiological Basis of Fibromyalgia	Dr David Andersson
11:55	Characteristics and pathophysiologic changes in a large cohort of Danish ME-patients.	Dr Jesper Mehlsen
12.20	*Lunch*	
13.20	Anne Örtegren Memorial Lecture: Pain and ME/CFS	Professor Stuart Bevan
13:45	Developments at Quadram Institute	Professor Simon Carding
14:05	Rituximab in ME/CFS: a randomised, double-blind and placebo-controlled trial	Dr Oystein Fluge
14.30	Metabolic profiling and associations to clinical data in ME	Professor Karl Johan Tronstad
14:55	Refreshments Break	
15:25	Integrative Medicine Approach to Treatment of ME	Professor Nancy Klimas
15:50	Harvard Plans for Clinical Research	Dr Ron Tompkins
16:10	Physiological and fMRI measures before and after symptom provocation by invasive cardiopulmonary exercise testing	Dr Michael VanElzakker
16:35	Stanford Metabolomics & Genetics Study Update	Professor Ron Davis
17:10	Plenary Session	Panel discussion
17.30	Adjourn	

Invest in ME Research (IiMER) was set up with the objectives of making a change in how ME is perceived and treated in the media, by health departments and by healthcare professionals.

We aim to do this by finding, funding and facilitating biomedical research, educating healthcare and lobbying for change in policies toward ME.

FAST TRACKING SOLUTIONS FOR ME

of Excellence for ME

investinmeresearch.org

#Let's research

Myalgic Encephalomyelitis (ME) is a serious, chronic disease
Help us develop a Centre of Excellence for ME - a research hub in Europe - enabling a strategy of high-quality biomedical research to develop - coordinated and collaborating with other institutes
www.investinme.org/research @Invest_in_ME @LetsDoIt4ME #CofEforME

Invest in ME Research (UK charity nr. 1153730)
www.investinme.org email: info@investinme.org