Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

March 2017

Future dates

Open to all members and carers.

19th April 2017 (Wednesday) 7.30pm White Lyon & Dragon
Perry Hill, Worplesdon, Guildford, GU3 3RE
www.whitelyonanddragon.com

17th May 2017 (Wednesday) 11.15am The Seahorse
The Street, Shalford, Guildford, GU4 8BU
www.theseahorseguildford.co.uk

12th June 2017 (Monday) 7.30pm The Weyside
Millbrook, Guildford, Surrey, GU1 3XJ
www.theweyside.co.uk

The ME Trust

The at-home service detailed below is for information only. It would seem appropriate to further understand both: how the service differs from typical NHS palliative care; and if the services potential interventions stem from either a biological or psychological concept of ME/CFS.

The ME Trust is the UK's only charity dedicated to funding and providing individual patient treatment for people with ME/CFS.

As well as listening and caring for the needs of the whole person, we offer encouragement and support to families, and immediate community of carers. We offer telephone consultations and home visiting services. An initial enquiry via our website will be forwarded to Hannah Clifton, our Director and the founder of the Trust. Hannah brings a deep understanding of what it can be like to have to live with ME/CFS.

She will offer a 15 minute telephone call free of charge and, if needed, forward your details to Dr Paul Worthley, a trustee of the ME Trust who has over 20 years' experience of helping people with ME/CFS.

An initial 15 minute telephone call with him to assess the best way forward is also free of charge. Subsequent telephone consultations with Dr Worthley would be at a rate of £40 per 30mins.

The ME Trust has limited funds, but may be able to assist in cases of financial need. This would be decided following discussion with our Director. We welcome donations to fund bursaries. Donate to help someone with M.E.

Dr Paul Worthley is often able to offer home visits, usually within the south/south-east of England. Depending on the travel time, the cost would be from £250.

We are currently looking at potential venues from which to offer face to face outpatient consultations.

Dr Paul Worthley
Dr Paul Worthley trained at St Bartholomew's Hospital, London, where he qualified in 1976. He spent three years at the Worcester Royal Infirmary, went on to general practice training in Hackney and then to two years' general practice in East London, before returning home to Australia where he worked at the Adelaide Children's Hospital from 1983 to 1987. He returned to Worcester to a variety of general practice and paediatric work before moving to Burrswood Hospital in Kent in 1992. In 1996 he obtained his Diploma in Palliative Medicine.

Working at Burrswood Hospital for 24 years, Dr Paul was resident Senior Physician until 2014 and for the last two years ran an outpatient clinic for people with ME/CFS and related illnesses. Working with physiotherapists and, more recently, an occupational therapist, he pioneered a whole person and individually tailored approach to caring for people with this spectrum of disease, which has benefited hundreds of patients. The value of his approach was confirmed by a Kent University study.

Dr Paul has over many years learnt a lot both from patients and by meeting the few medics who work in this field. He has gained an expertise in the area of ME/CFS and has helped hundreds of ME/CFS patients.

Contact details
Address: The M.E. Trust, 16 Old Bailey, London, EC4M 7EG
Email: info@metrust.org.uk
Website: www.metrust.org.uk/contact

Metabolic switch may bring on ME/CFS

Source: www.newscientist.com/article/2121162-metabolic-switch-may-bring-on-chronic-fatigue-syndrome

By Andy Coghlan February 2017

It's as if a switch has been flicked. Evidence is mounting that chronic fatigue syndrome (CFS) is caused by the body swapping to less efficient ways of generating energy.

Several lines of investigation are now suggesting that the profound and painful lack of energy seen in the condition could in many cases be due to people losing their ability to burn carbohydrate sugars in the normal way to generate cellular energy.

Instead, the cells of people with CFS stop making as much energy from sugar as usual, and start relying more on lower-yielding fuels, such as amino acids and fats. This kind of metabolic switch produces lactate, which can cause pain when it accumulates in muscles.

Together, this would explain both the shortness of energy, and why even mild exercise can be exhausting and painful.

Sex differences

Øystein Fluge of Haukeland University Hospital in Bergen, Norway, and his colleagues studied amino acids in 200 people with CFS, and 102 people without it. The levels of some amino acids in the blood of women with CFS was abnormally low – specifically for the types of amino acid that can be used by the body as an alternative fuel source.

These shortfalls were not seen in men with CFS, but that could be because men tend to extract amino acids for energy from their muscles, instead of their blood. And the team saw higher levels of an amino acid that's a sign of such a process.

"It seems that both male and female CFS patients may have the same obstruction in carbohydrate metabolism to energy, but they may try to compensate differently," says Fluge. Both sexes had high levels of several enzymes known to suppress pyruvate dehydrogenase (PDH), an enzyme vital for moving carbohydrates and sugars into a cell's mitochondria – a key step for fully exploiting sugar for energy.

Fluge thinks PDH is prevented from working in people with CFS, but that it can spontaneously recover.

Starvation effect

Several studies have now hinted that defects in sugar burning can cause CFS, but there is still uncertainty over how exactly this is disrupted. However, a picture is emerging. Something makes the body switch from burning sugar to a far less efficient way of making energy.

"We don't think it's just PDH," says Chris Armstrong at the University of Melbourne in Australia, whose research has also uncovered anomalies in amino acid levels in patients. "Broadly, we think it's an issue with sugar metabolism in general."

The result is not unlike starvation, says Armstrong. "When people are facing starvation, the body uses amino acids and fatty acids to fuel energy for most cells in the body, to keep glucose levels vital for the brain and muscles as high as possible."

"We think that no single enzyme in metabolism will be the answer to CFS, just as no single enzyme is the 'cause' of something like hibernation," says Robert Naviaux of the University of California at San Diego, who has found depletion of fatty acids in patients suggesting they were diverted as fuel.

Not psychosomatic

So what could flick the switch to a different method of metabolism? Fluge's team thinks that a person's own immune system may stop PDH from working, possibly triggered by a mild infection.

His team has previously shown that wiping out a type of white blood cell called B-cells in CFS patients seems to relieve the condition. These white blood cells make antibodies, and Fluge suspects that some antibodies made to combat infections may also recognise something in PDH and disable it.

The team is now conducting a large trial in Norway of the cancer drug rituximab, which destroys the cells that make antibodies, in people with CFS. Results are expected next year.
Together, these metabolic approaches are suggesting that CFS has a chemical cause. "It's definitely a physiological effect that we're observing, and not psychosomatic, and I'll put my head on the block on that," says Armstrong. However, he adds that psychological and brain chemistry factors might be involved in some cases.

Journal reference: Journal of Clinical Investigation, DOI: 10.1172/jci.insight.89376

Stanford team announces breakthrough in ME/CFS research

Source: www.meaction.net/2017/02/22
22nd February 2017 by Adriane Tillman

A research team at Stanford announced yesterday that it has made some breakthroughs in understanding the metabolic cycles that are not working properly in people with ME/CFS that might be at the heart of the disease.

Ronald W. Davis, PhD, made the announcement via YouTube. Davis directs the CFS Research Centre team at the Stanford Genome Technology Centre (SGTC).

Problems with metabolic cycles
The team's metabolomics tests on severely-ill patients revealed problems with the citric acid cycle. Participants' blood work showed that some of the chemicals involved in the citric acid cycle are very low, making it difficult for the patient to generate the chemicals we use for energy. Several chemicals were found to be two standard deviations away from those of healthy controls, which is serious, according to Davis.

Recent research by Fluge and Mella has also suggested that pyruvate dehydrogenase, the enzyme that helps glycolysis transition into the citric acid cycle, may be blocked.

"We have not investigated that, but it is consistent with glycolysis being shut down," Davis said. "We also think that pyruvate kinase might be shut down. Those are not inconsistent and it is possible there are blocks in both of them."

Technology to screen drugs without using patients
Davis also announced a device that the Stanford team has developed to test metabolic functions, which will enable them to do mass screenings of drugs without the time and cost restraints of using patients.

The device is about the size of a computer chip. It has a small channel in it to accommodate a tenth-of-a-drop of blood all that is needed for this assay. It has 2500 electrodes in it, and each electrode is sampled 200 times a second. This generates a massive amount of data.

Davis explains how the device works:
"What we have noticed from this device is that if we put bacterial population into this, we will get a certain electrical impedance signal. If we then add an antibiotic that kills the bacteria, the electrical impedance will rapidly increase. If the bacteria are resistant to the antibiotic, we see no change.

"So, if we put healthy cells and their serum into the device, it is pretty stable and does not change. If we put in ME/CFS cells and their serum, it doesn't change. However, if we put a demand on the cells, we require them to consume energy, and that demand is seen in this graph where there is a slight dip in the healthy controls – but they handle that demand quite well and don't change after that – however the cells from the ME/CFS patient shows a rapid increase in impedance. And that has been shown for every patient we have looked at, and also every healthy control is the same."

Most importantly, the device provides a way for Davis and his team to test drugs on ME/CFS cells and serum to see the effect.

Davis noted that the rapid rise in impedance is caused by the serum, not the cell, which means that there is something being released into the serum that may be causing or contributing to symptoms.

“If it is in the serum, we probably can find it,” Davis said. “And that is what we’re trying to do now, which is find the component or components – most likely plural – that is causing this effect… Now this a good hypothesis, and we are now testing it.”

Davis said that the next step is to use the device to test the effects of various drugs on the cells and serum of ME/CFS patients. For example, Davis’ team found that adding ATP to unhealthy ME/CFS cells and serum made the cells respond normally. The team also plans to test drugs that many ME/CFS patients have reported helpful using this device, such as Valcyte and Rituximab.

If the device turns out to be a good diagnostic test for ME/CFS, Davis said his team will disseminate information to doctors’ offices.

Jen Brea's TED talk

Source:
www.prohealth.com/library/showarticle.cfm?libid=29909

By Cort Johnson

There's no need to embellish chronic fatigue syndrome (ME/CFS; ME) stories. Shakespearean in their depth, ME/CFS stories can be so disturbing that some people will undoubtedly look for ways to dismiss them. Healthy, active, successful people, after all, don't suddenly end up in bed for decades for reasons doctors can't explain. At least not in most people's reality.

That's why telling our stories in a calm, matter of fact but forceful manner is best. Adding a touch of humour is really good. Talking to the audience like they're in your living room - is even better. Including their concerns in your story - now, you're really talking. Jen Brea does it all in her outrageously successful TED talk on chronic fatigue syndrome.

By itself her story is powerful and moving. The shocking collapse of the young, active PhD student: healthy one day, disabled the next. The seemingly ordinary infection, the exhaustion, the strange neurological symptoms, the years in bed, the innumerable lab tests, the fruitless doctor visits, the conversion disorder diagnosis (by a neurologist not a psychiatrist), the terrible relapse after exercise, the lack of help from the medical profession. Jen's nightmarish story with her always evocative visuals (including a moving one of Whitney Dafoe in pain) will undoubtedly wake up many.

For those who missed the boat the first time around, Jen's masterful punch line - that what happened to me could happen to you, and not just if you have ME/CFS - should capture them. Her assertion that being a woman means being in danger of having an illness downplayed or turned into hysteria or anxiety will resonate. The idea that what's happened to ME/CFS is part of a broad historical trend that any woman could be touched by someday is a powerful one that could help enrol many.

While she didn't mention them, other primarily woman's disorders such as fibromyalgia, IBS, migraine, interstitial cystitis, vulvodynia and ME/CFS that affect millions have been virtually ignored by the NIH. The pattern is clear; if you have an "invisible illness", most of which happen to women, you're in real trouble.

After seeing the tremendous increase in immune disorders over the past couple of decades - which, again, has mostly fallen on women - one has to ask why, as Jen put it, women's immune systems aren't as much a battleground for equality as other issues.

Why organizations like the National Organization for Women (NOW) have never taken on the conversation in the medical profession that allows it to side-line diseases affecting millions of women year after year after year.

Being a great communicator is just one part of making a difference. There's also the art of getting the message out. Few are good at both. Jen is obviously good at both. She's the first person with M.E. that I can remember who's been able to get to the TED stage. As a blogger who watches internet traffic pretty closely I can tell you that getting 160,000 views in three days is unimaginable. For an illness which counts its internet traffic in the tens of thousands - reaching 160,000 people, most of whom probably know little about it - is beyond believable.

Jen undoubtedly would have been successful whatever she ended up doing, but I doubt she would have made the difference she has now. If you haven't seen Jen's 17 minute TED talk, please consider passing it on to everyone you know.

https://youtu.be/Fb3yp4uJhq0

'25% Group' and 'Stonebird' response to BACME article on care provision for severe ME

Source: http://carersfight.blogspot.co.uk/2017/03/25-group-and-stonebird-response-to.html

The BACME (British Association for ME/CFS) seem to be an organisation supporting both NICE guidelines for ME/CFS and PACE trial results, operating to a psychosocial concept of ME/CFS.

The BACME recently released a Clinical Practice Guide for Severe ME/CFS. Below is a response from:

25% Group

www.25megroup.org
A charity in support of Severe ME/CFS

Stonebird

www.stonebird.co.uk
A Severe ME website by Greg & Linda Crowhurst

When you work with someone who has Severe ME you need to be more sensitive and aware than you can possibly imagine. Harm, even death for some, may follow poor treatment, care and ignorance.

The frailty of someone with Severe/Very Severe ME cannot be exaggerated nor adequately described. You need to take the greatest of care.

The problem with this BACME document is its underlying psychosocial values and attitudes. If you expect a person to get better, that will be your intention, that will be your goal, that is going to influence all your thoughts and actions in your caring role, especially if you set goals or limit care over time.

The care provided by someone with a biomedical understanding of Severe ME is going to be fundamentally different.

The most important aspect of caring for a person with Severe Myalgic Encephalomyelitis (ME) is the 'how' of caring; the basic core beliefs that the carer has about caring and the person to be cared for. What the carer believes will subtly or overtly impact on how caring is provided and has a huge effect on the relationship, quality of care and health of the person receiving the care.

Great harm can be done by someone who is not fully aware that the person with Severe ME is seriously physically ill and that they are not going to be “made well” by changing their thoughts or increasing their activity in a graded way, as this dangerous document from BACME suggests.

The basic principles behind Severe ME-aware care are:

- never define the person by their behaviour;
- acknowledge the serious and severe physical illness underlying the person’s symptom experience;
- adhere to a strictly defined definition of ME (International Consensus Criteria);
- honour the WHO classification of ME as a neurological disease and respond appropriately and equally as in any other recognised neurological disease;
- treat the person with respect on all levels; respect for the way interaction occurs, the physical and the cognitive limitations enforced on the person by their severely disabling multi-system dysfunction;
- honour what the person says regarding their physical and cognitive needs;
- listen to the person and to only interact at the correct time in the correct way. We call this the MOMENT approach, honouring the severe illness the person has whilst maximising the opportunity to engage safely in order to help, not harm them, when undertaking all care needs. (Crowhurst 2015);
- understand any hypersensitivity issues (chemical, drug, touch, noise, light, movement, motion, food); never ignore, undermine, negate or belittle them, recognising the danger of the ordinary environment as real, not just perceived;
- understand and comprehend that the person with Severe ME is not experiencing the world the same way as a well person and cannot fit into the demands and obligations imposed on them by others, easily or at all. A flexible, knowledgeable, sensitive, compassionate, non-judgmental, person-centred not goal oriented approach at all times is critical. Being aware of the after impact of any interaction is essential; that even something once achieved cannot necessarily be achieved or tolerated again or regularly or increased; and
- recognise the irrelevance, unhelpful and dangerous nature of a psychosocial response and interpretation of Severe ME, a physical disease. Psychiatry has no right to first hand intervention in this disease which requires a biomedical response and care pathway.

It is vital to ensure that that you never put any overt or covert pressure, demand or expectation to improve, upon the person with Severe ME, nor any underlying belief that is in opposition to the truth and severity of the disease and very real lack of valid treatment and cure.

In ME when you push yourself you deteriorate, whether immediately or delayed, if you push too hard you may even enter worse illness experience than you have already experienced, beyond which you may not be able to recover from at all or only partly. The depth and level of physical and cognitive deterioration and harm that can follow is literally unimaginable before it occurs.

The impact can be permanent or very long term. There are many good observations and insights into the reality of Severe ME in the BACME document; but its expectations of recovery that could impose unreasonable, unrealistic, even fatal demands, render it extremely dangerous.

Anyone who believes the message that people with Severe ME can do more than they physically can, by thought and activity, even if only over time, no matter how genuinely they believe it or how nice they are or how encouraging they are, can so easily do untold harm because they will exact subtle if not overt pressure, however kindly, upon the person to improve.

A carer following this BACME guide, we fear, is unlikely to be able to separate care from treatment, to comprehend the importance of flowing with the person, just to help them cope, rather than set goals for "recovery", however seemingly small from the well perspective nor appreciate the long term commitment just to improve quality of life and comfort rather than quality of thought and ability.

There is no place for complacency, mediocrity or carelessness in the life of someone with Severe ME. A carer's interventions can cause serious harm to the person's health. As the PACE and FINE Trials have shown, the psychosocial approach that this guide is constructed upon, is bound to fail and not just fail but cause real harm. (Vink 2017). It must be viewed within its psychosocial context, this BACME document cannot possibly be recommended for anyone with WHO G93.3 defined Myalgic Encephalomyelitis.

References

Crowhurst G (2016) The MOMENT Approach http://stonebird.co.uk/main/index.html

BACME Working Group on Severe CFS/ME Shared Clinical Practice Document Version 1 (2017) http://measussex.org.uk/severely-affected-guidelines-february/

Vink M (2017) Assessment of Individual PACE Trial Data: in Myalgic Encephalomyeli-tis/Chronic Fatigue Syndrome, Cognitive Behavioral and Graded Exercise Therapy are Ineffective, Do Not Lead to Actual Recovery and Negative Outcomes may be Higher than Report-ed. J Neurol Neurobiol 3(1): doi http://dx.doi.org/10.16966/2379-7150.136

Take part in the Big Benefits Survey

Source: www.actionforme.org.uk/news/take-part-in-the-big-benefits-survey

The Disability Benefits Consortium (DBC) has just opened its Big Benefits Survey, which asks disabled people to share their experience of the benefits system. People with M.E. are encouraged to take part.

The DBC is a national coalition of over 80 different charities, including Action for M.E., which campaigns for a fairer benefits system.

Disabled people often struggle to get the financial support they need, and the purpose of the survey is to get a wider understanding of how the benefits system can be improved. This survey takes place each year, and monitors how the benefits system is working for disabled people as well as gathering evidence to support the work of the DBC. In previous years, over a thousand people have responded.

You will only be asked about the benefits you've applied for, with the possible options being:

- Employment and Support Allowance (ESA)
- Personal Independence Payment (PIP)
- Attendance Allowance (AA)
- Universal Credit (UC)

Responses will be anonymous, unless you offer to be contacted further. The survey is open now and will run on an ongoing basis throughout 2017.

The survey will take between 10 and 30 minutes to complete. In order for us to understand your experience of the whole process of applying for disability benefits, this survey is best completed once you have gone through your application(s) and know the outcome. However, you are welcome to complete it if you have yet to go through your application process.

Your views are important and will help us, as a group of charities to tell the Government about ongoing problems and issues with the benefits system that need to change.

You can access the survey here:
http://surveys.parkinsons.org.uk/s/bigbenefitssurvey

Animal Touch

Website: https://animaltouch.org

"Animal Touch" is the UK's first and only complete farm animal therapy centre based in Hook, Hampshire.

The charity Animal Touch was established to offer any individual or group the opportunity to share one to one therapeutic or fun time with our animals. We have welcomed many people of different ages, needs and backgrounds coping with the daily challenges of their lives. You can book a session that is right for you, your family member or support group; or why not enjoy a birthday party or time together for the whole family.

We have a wide variety of friendly farm animals:

Miniature donkeys	Pigs and piglets
Sheep and lambs	Ducklings
Goats and kids	Chickens
Rabbits and Guinea pigs	

All visitors can interact closely with our animals - cuddling, feeding and grooming. Our priority is to make a safe and welcoming space for anyone who wants to escape the everyday stresses of their life and enjoy the magic of our special farm.

All our animals enjoy human contact and their happiness and welfare is hugely important to us. We know a visit to Manor Farm can inspire energy and hope. Here at Animal Touch everyone is welcomed and appreciated by the team and animals just as they are.

I look forward to welcoming you to the farm soon, Elizabeth Miller and the Animal Touch team.

Our mailing address is:
Animal Touch, Manor Farm, Blackstocks Lane, Hook, Hampshire, RG27 9PH

Call 01256 767596 or email elizabeth@millersark.co.uk

An ME Electronic Health (eHealth) System

The following information was emailed to our group and is for information purposes only. As the Newsletter Editor I only know what you read here and in Appendix 1 of this newsletter. Any involvement with the eHealth system is at your own risk.

Dear Guildford ME Group
My youngest son is an ME patient who suffers from severe ME. I am a research scientist, an ex-senior lecturer and a psychologist. My wife is a bio-statistician and we have been carrying out research on ME for the last four or five years.

As you will know, ME patients are widely dispersed and often isolated and have problems in communicating with the world, in particular, with health and social work professionals.

To help overcome these problems we are hoping to establish, in co-operation with Southampton University's Electronic Health Department, an "Electronic Health (eHealth) system", which will enable patients to establish a two-way secure digital communications system. The aim is to enable patients to take a more active role in managing their own health. It will enable them to order repeat prescriptions, increase preventative care, book on-line appointments and interviews, and share information with other ME patients and much more.

It will also assist them in obtaining clinical drug trials and treatments leading to a cure, something ME patients want, above all else.

Initially we are planning a pilot study involving mainly counties across the South Coast from Devon to Kent. I have identified thirty five ME groups in this area and I am emailing all of them, including yourself, asking them to take part in the study.

A Working Team. To undertake this work we would like to establish a small team of people with an interest in ME who can help. We are looking for practical people with a track-record of getting things done and plan to establish a video link using Skype so we can “meet on-line”, hence there would be little traveling involved. If you or anyone you know might be interested I would be glad to hear from you or them.

Where will the money come from?
Electronic Health is a large and fast growing world market. England, Ireland, Scotland and Wales all have plans in place to digitise their health systems by 2020. Over the present parliament, the treasury has set aside £4.2 billion to invest in digital projects and the GP's Clinical Commissioning Groups will invest a further £99 million in establishing e-Health systems. In addition, in September 2016, NHS England awarded twelve hospitals designated “Digital Exemplars” a further £10 million pounds each. The University Hospital at Southampton’s was one of them.

Countries all round the world have installed eHealth systems or have plans to do so. By 2010 America had invested $62 billion in digital health and further investments are being made in the USA. Forty two EU countries have already invested in eHealth and the same pattern of investment is taking place in all parts of the world.

Why are so many investing in eHealth?
First because it is saving money, typically around 30 to 40% in those systems that are under pressure from aging populations and increasing demands for health care etc. Witness the current problems of the NHS. Second and more importantly, it has been shown to improve healthcare, help prevent ill health and help with social problems.

Why ME and why now?
In the UK a great deal of time, money and effort has been wasted on eHealth systems that were overly centralised, bureaucratic and abstract. In contrast M.E. provides a concrete basis for showing what eHealth can achieve.

There are an estimated 200,000 ME patients dispersed throughout the UK. (30,000 along the south coast) Its symptoms are well-defined and, in the last ten years alone, ME has been the subject of more than 2,750 biomedical research studies. So before everyone else jumps on the bandwagon now is the time for ME patients to get involved in eHealth.

Electronic Health is complicated and I have taken the liberty of attaching a short paper on the subject (see Appendix 1 of this newsletter) which I hope you will find helpful.

We are establishing an eHealth group on Facebook so as to contact as many ME sufferers and their supporters as possible. It will be called, “Electronic Health for ME” If you or any members of your group and supporters would like to join us on Facebook, please do. If you have any problems or queries do not hesitate to contact me either at my email address or by phone on 02380 558621.

I look forward to hearing from you.
Yours sincerely
Dr Lionel Wardle

The Guildford & West Surrey ME/CFS Group newsletters aim to inform members of relevant news and treatment options. Use of the treatments is done at your own risk.

Appendix 1

Electronic Health (eHealth) for ME

Myalgic Encephalomyelitis (ME)

Electronic Health (eHealth)
Electronic Health might well have been designed to meet the special needs of ME sufferers and other rare disease patients, For the most part such patients are widely dispersed and many are house and bed-bound 24/7, isolated and often lonely.

To get to a hospital or see a GP, often an ambulance is needed or else a GP has to come and visit them (which doesn't often happen). Going digital allows them get rid of paperwork, increase security and cut costs both for themselves and the NHS. It enables them to order repeat prescriptions, book on-line appointments, establish two-way communications with health and social workers and to share information with others in situations similar to their own. It enables large-scale patient records to be analysed to find disease patterns that would otherwise not be seen or recognised and so much more

eHealth is defined by the European Commission as the use of:-

"Secure modern information and communications technologies (ICT's) to meet the needs of citizens, patients, healthcare providers, professionals, and policy makers."

The **diagnostic symptoms** of ME are well defined in the International Consensus Criteria (ICC) of 2011. This makes it easier for ME patients to check that any given medical **application** (app) is relevant to their condition. (I will publish a brief intro' in my next blog to the diagnostic symptoms of ME).

Mobiles, wearables and portable apps are an important and visible part of eHealth. In 2014 there were some 40,000 **mobile health apps** available and by 2017, this number is set to almost double, with a market value of some $26 billion. Such programs already cover many of the diagnostic symptoms defining ME including cardiovascular and neurosensory problems, immune, autoimmune, and gastrological symptoms, pain, disturbed sleep patterns and difficulty in breathing. ME symptoms not covered by medical apps, (so far as I am aware), include **Post-Exertional Malaise (PEM)**, a condition that occurs after exertion, no matter how trivial and from which it can take months to recover, **Postural Orthostatic Tachycardia** (**POTS**), a condition in which a change from lying down to an upright position causes abnormally large increases in heart rate. If anyone knows of an app that covers these conditions I would be glad to hear from them.

Big Data

A component of eHealth which tends to be overlooked is the use and analysis of electronic patient records. This usually referred to as "Big Data analytics".

Such data can readily be adapted to monitor ME and other rare diseases and can be down-loaded to a GP, health centre and nurses or social workers with a few clicks of a button, creating a central registry of "Big Data" which can readily be used for disease prevention, clinical treatment, monitoring, and research.

What **can** be achieved from electronic patient records was well demonstrated by Scotland as long ago as 2011. They established **eHealth records** for 240,000 diabetic patients, showing the medications prescribed for them and whether they had agreed to take part in clinical trials. Those that agreed could be contacted directly by phone or email and asked to take part, this way it took just two weeks to recruit patients for clinical trials.

This is still the fastest rate in the world and compares with about three months in the USA and England. In addition to saving time and money Scotland's eHealth records also increased the likelihood of improved patient's health which is much more important.

Over a period of six years these eHealth records led to a reduction in **eye problems** due to diabetes by **4O%** and over the same period a reduction in **amputations** by **43%.** These patterns in the eHealth data not readily observable.

In 2002, the UK was second only to America and Germany in carrying out clinical trials, but sadly by 2006, UK clinical trials declined steeply. We are now in ninth position and still declining. It matters - the UK has 4,500 pharmaceutical and biotechnology companies that together employ 165,000 people with an annual turnover of some £50 billion. But clinical trials are about more than jobs and money. They also provide opportunities for patients to take part in such trials and of accessing new products before they reach the market and much more.

When establishing clinical trials, drug companies look mainly to three factors:

1. Time taken to establish the trial and meet the regulatory and ethical requirements.
2. Cost, time and effort required to recruit patients with the relevant characteristics.
3. Cost of carrying out the trial.

Electronic Health can do much to meet and reduce these factors as shown by Scotland in 2011. They reversed the decline in clinical trials and in one example brought in an extra £1.2 billion.

Including ME there are an estimated 7,000 rare diseases world-wide but this is figure is misleading since about 80% of patients (about 280 million) are affected by just 350 diseases.

Prior to 1983, most Pharmaceutical companies were not prepared to invest in rare diseases. They are in business to make money and they did not believe they would get their money back, let alone make a profit from such research.

In 1983, the American Government introduced the **Orphan Drugs Act**.(**ODA**) This provides significant incentives for companies willing to undertake research on rare diseases including tax relief, extended patents, funding for research and much more. The Act proved to be a great success and **countries around the globe**, e.g. the EU, Australia, Japan, and South Korea etc. all enacted their own Orphan Drugs Act. By 2015 the Orphan drug market was worth an estimated **$100 billion dollars per annum.**

M.E., has been the **subject of more biomedical research projects than any other rare disease**. One reviewer claimed that since the 1930's it had been the subject of some 9,000 studies. I can't vouch for that, but the figure is plausible. What I can say is that in the ten year period prior to 2015 more than 2,750 studies were carried out. I know because I counted them. Sadly there are almost no follow-up studies of this research. The usual excuse is lack of money and resources, but in this case I doubt this is true.

Most shocking of all, is that **only one of those studies** was a clinical trial looking for a cure. This trial happened by chance in Norway in 2004. It was carried out by Drs Fluge and Mella who were treating a woman with cancer with a drug called "rituximab".
Their patient also happened to have ME and they found that their rituximab treatment cured her ME. To prove their findings they have been carrying out clinical trials for the last 14 years and hope to report and confirm their findings by the end of 2017.

What ME patients **want before all else are clinical trials leading to a cure**. So why so few clinical trials? The short answer is lack of money and resources. This is an ironic and sad excuse since the money and resources are available to any rare disease registered under one or more of the Orphan Drug Acts - but ME is **not** registered, no one has applied to register it.

To be registered the main requirement is to prove that ME is a **rare disease**, defined globally as one with a prevalence of less than 0.5%. With the help of my wife (A professional statistician with a Masters in Biostatistics) we have produced valid and reliable evidence from a number of published sources that ME has a prevalence of around 0.3%.

Clinical trials are important and complicated and we will be publishing separate blogs on this topic. With the help and cooperation of local ME groups and one or more pharmaceutical companies we hope to apply for ODA registration and funding.

Orphan Drug Acts are another complicated topic. You can apply for ME to be registered in the ODA's of different countries, all at the same time and hence you can simultaneously work on different symptoms of ME. How this can be achieved will be the subject of a separate blog.

I would be grateful to hear from anyone working with an eHealth system. In particular:-

a) **The outcomes** and what has been achieve in terms of health and otherwise

b) **What computer and ICT system they are using**, including the advantages and disadvantages of that system and how it might be improved.

In establishing an ME or rare disease eHealth system we are hoping to cooperate with one or more Universities e.g. Southampton and perhaps other eHealth organisations. I would be glad to hear from anyone who can make a positive contribution to such a project. I live a short walk away from Southampton University eHealth Department.

My background

My youngest son has had severe ME for the last seven years. I am a polymath, and ex-Senior Lecture in Management and Industrial Psychology with a PhD in the Psychology of Mathematics from Southampton University. . My wife is also a polymath with a Masters in Systems Analysis.

Amongst other things, between us we ran a successful business in computer training for professional groups, including **"Computer holidays for GPs**," teaching them how to install and use computers in their practise.