Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

June 2018

Drawing by CFS sufferer Shantel Palmer

Future dates

Open to all members and carers

9th July 2018 (Monday) 11.15am The Seahorse
The Street, Shalford, Guildford, GU4 8BU
www.theseahorseguildford.co.uk

8th August 2018 (Wednesday) 7.30pm The Weyside
Millbrook, Guildford, Surrey, GU1 3XJ
http://www.theweyside.co.uk
(Parking at Millbrook car park £1 for evening)

10th September 2018 (Monday) 11.15am The Seahorse
See earlier above for location details

Westminster Hall debate could be a ‘turning of the tide’ for ME

Source: www.meaction.net/2018/06/21/westminster-hall-debate-is-turning-of-the-tide-for-me/
21st June 2018

#MEAction UK have made our group aware of the recent Westminster Hall debate on ME. And also a link to a video that shows a recent petition to the Public Petitions Committee of The Scottish Parliament.

21st June 2018 was a turning of the tide for Myalgic Encephalomyelitis (ME) as 26 MPs attended a Westminster Hall debate on treatment and research for ME. MPs called for the immediate removal of Graded Exercise Therapy (GET) from the NICE guidelines, as patients have consistently reported being harmed from attempting to undergo this treatment. MP Ed Davey called for the suspension of the GET guideline, suggesting that not doing so risks litigation.

“Never have I felt so heard,” said Sian Leary from Sheffield who has been housebound with ME for the past 5.5 years. “Today is the day, here, in June 2018, where finally we started to take Myalgic Encephalomyelitis… seriously and we stopped condemning people who suffer from this ghastly debilitating disease,” said MP Stephen Pound, one of the 6 MPs who petitioned for the debate. “Today is the day we said, “Yes we understand the pain people suffer . Yes we’re going to do something about it. Yes we respect you. Yes we value you. And yes today we’re going to start investing in diagnosis and analysis and, god willing, cure”.

Carol Monaghan MP, who had led the petition for the debate, said that Professor Sharpe, one of the authors of the PACE trial, emailed her this week to tell her that her behaviour is “unbecoming of an MP”. “I say to Professor Sharpe that if listening to my constituents, investigating their concerns and taking action as a result is “unbecoming”, I stand guilty. [Hon. Members: “Hear, hear!”] If Members of Parliament are not willing to stand up for the most vulnerable in society, what hope do any of us have?”. MP Liz McInnes spoke about how GET had worsened Merryn Croft’s condition. Merryn Croft, 21, died from severe ME.

Health Minister Steve Brine, MP, welcomed the NICE’s decision to undertake a full review of ME guidelines, but avoided taking responsibility saying, “It would be inappropriate and wrong for Ministers to interfere with the process, but I feel sure that NICE will be listening to the debate and taking a keen interest in it.”

A transcript of the debate is available here:
https://hansard.parliament.uk/Commons/2018-06-21/debates/A49A6117-B23B-4E35-A83B-49FEF0D6074F/METreatmentAndResearch

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The link on the following page will take you to a video of the Petition to The Scottish Parliament by Emma Shorter on behalf of ME Action in Scotland on ‘Review treatment of people with ME in Scotland’

Evidence comes from - Emma Shorter and Janet Sylvester, volunteers with MEAction Scotland, and Prof. Chris Ponting, Chair of Medical Bioinformatics at Edinburgh University and Deputy Chair of the UK CFS/ME Research Collaborative.

The Scottish Parliament
Pàrlamaid na h-Alba

https://www.scottishparliament.tv/meeting/public-petitions-committee-june-7-2018?clip_start=10:10:45&clip_end=10:55:17

People with M.E. must be heard, says NICE committee

Source: www.actionforme.org.uk/news/people-with-me-must-be-heard-says-nice-committee
May 29, 2018

Action for M.E. joined stakeholders from patient groups, charities, and professional bodies to take part in Friday's workshop on the scope of the National Institute of Health and Care Excellence (NICE) guideline on M.E/CFS.

The event was part of NICE's ongoing process to revise its M.E./CFS guideline, with a focus on topics and themes that should be considered for inclusion, rather than the content itself. These included the need for:

- specific consideration to be given to children, young people and adults who are severely affected
- objective outcome measures to be prioritised by the committee when reviewing evidence about what to include
- a section about prevention, risk factors and deterioration to be included in the guideline scope.

"Points raised in my particular discussion group included the clear need for the guideline to reflect our current understanding regarding the aetiology of M.E. – and be clear on what M.E. is not, eg. deconditioning, or Medically Unexplained Symptoms," says Clare Ogden, Head of Communications and Engagement, Action for M.E., who attended the workshop. "We also asked that the consultation period on the draft scope be extended from four weeks, so that everyone with M.E. has the chance to have a say, including those severely affected."

Those attending the workshop were introduced to the Chair of the guideline development committee for M.E./CFS, Dr Peter Barry, and the Vice-Chair, Baroness Ilora Finlay. Dr Barry, who chairs two other guideline committees, said he was not an expert in M.E./CFS, and that coming to the topic without any preconceptions would be helpful. He also stressed the importance of recruiting the right professionals and lay members – or "experts by experience," the term preferred by Baroness Finlay – to the committee.

"There was a clear commitment from Dr Barry to ensure that the voices of people directly affected by M.E. are not just heard, but listened to, as part of guideline development," says Clare. "One of the key points raised at my discussion table was the need for committee members to be recruited on the basis of their commitment and integrity – not their job title. It was also suggested that an expert in internal medicine and/or clinical or molecular science might be useful."

The NICE team managing the guideline revision will now produce a draft scope based on discussions at the workshop, and consult on this with registered stakeholders from Thursday 21 June; recruitment for committee members will begin at the same time. Action for M.E. will be launching a survey to inform our response to this consultation, ensuring it is led by the views and experience of people affected by M.E.

A letter to the WHO asks for increased funding and recognition of ME/CFS

Source: www.prohealth.com/me-cfs/library/may-12-letter-world-health-organization-81079

Following is a letter sent to the World Health Organisation by The International Alliance for M.E. to increase international recognition of and funding for ME/CFS.

Dr Tedros Adhanom Ghebreyesus
World Health Organisation
Avenue Appia 20
1202 Geneva

11 May 2018
CC Dr Svetlana Akselrod, Assistant Director General for Non-Communicable Diseases and Mental Health

Dear Dr Tedros

Urgent action to address M.E. globally: a neglected NCD

Tomorrow, on 12th May, people across the globe will come together in public spaces, at government buildings, online and in their homes to ask: 'Can you see M.E. now?' You can see their films, photographs and stories, shared for this global M.E. Awareness Day event, at http://www.facebook.com/MEActNet and www.twitter.com/IAforME

M.E. (Myalgic Encephalomyelitis) is a complex, disabling, chronic, fluctuating, neurological condition of unknown aetiology. It is sometimes diagnosed as Chronic Fatigue Syndrome or CFS/M.E. It is a disease which affects 20,000,000 individuals of all ages and from all ethnic groups – and the families around them – causing significant personal, social and economic hardship.

The US government's landmark report, Beyond M.E./CFS: redefining an illness, made it clear that M.E. is 'a serious, chronic, complex, and systemic disease that frequently and dramatically limits the activities of affected patients. In its most severe form, this disease can consume the lives of those whom it afflicts.'

M.E. is associated with neurological, immunological and energy-metabolism impairment, and is characterised by significant disability and a widespread intolerance to even small amounts of mental and physical exertion. Other symptoms include sleep dysfunction, dizziness, widespread pain, cognitive dysfunction, and sensitivity to light and sound. We know that:

- one in four people with M.E. are so severely affected that they are unable to leave their beds or homes, sometimes for many years, too ill to bear even the touch of a loved one
- M.E. has the lowest health-related quality-of-life score when compared to cancer, diabetes, lupus, stroke, heart disease and chronic renal failure
- people with M.E. are at an increased risk of cancer, heart disease, and suicide
- in children and young people, the disease is the most common cause
- of long-term school absence.

Despite this suffering and disability, and the urgent need to find effective treatments, only 0.02% of international mainstream research funding has been directed towards M.E.5 Moreover, the condition is frequently undiagnosed, misdiagnosed and/or mistreated by physicians and often not recognised by national treatment and health insurance systems.

The International Alliance for M.E.'s awareness event on 12th May in Geneva, just one of thousands of Millions Missing events across the world, is part of our work to highlight the challenges faced by people with M.E.

We would greatly appreciate it if you could make time in your busy schedule to meet representatives from the International Alliance for M.E., a new collaboration uniting M.E. organisations in the US, Australia, Spain, Japan, South Africa and the UK. We would like to highlight the serious and significant impact of this often unrecognised condition, and explain why we are seeking urgent national and international action to increase research on the condition and ease the suffering of patients around the world.

We hope that, with the support of Members States and WHO, we will:

1. Recognise M.E. as a 'serious, chronic, complex, and multisystem disease that frequently and dramatically limits the activities of affected patients'7 and adopt measures to provide a global and co-ordinated public health response to it.
2. Put in place transparency and a consultation process with M.E. organisations and patients on decisions related to M.E.
3. Support accelerated biomedical research to develop better diagnostic methods and treatments for M.E.
4. Ensure appropriate medical education for professionals working with M.E. patients.

As advocates, organisations, patients and carers, the International Alliance for M.E. is determined to see the condition properly recognised and treated, working with scientists and researchers across the world. We very much hope for your support for people living with M.E.

In the hope of your favourable reply to our invitation to meet,

Yours sincerely

- The International Alliance for M.E.
- ACAF – Associacio Catalana d'Afectades i Afectats de Fibromialgia i d'altres Sindromes de Sensibilitzacio Central, Spain
- Action for M.E., United Kingdom
- The American ME and CFS Society, United States
- Emerge Australia, Australia
- Forward ME, United Kingdom
- Japan ME Association, Japan
- ME CFS Foundation South Africa, South Africa
- Plataforma Familiars Fm-SFC-SQM, Spain
- Solve ME/CFS Initiative, United States

With support from

- Association du Syndrome de Fatigue Chronique, France
- Lost Voices Stiftung (Foundation), Germany
- #MEAction, United Kingdom
- ME/CFS Association Switzerland/Verein ME/CFS Schweiz, Switzerland
- ME/FM Society of BC, Canada
- ME Research UK, United Kingdom
- Millions Missing Canada, Canada
- Millions Missing France, France
- National ME/FM Action Network, Canada
- Open Medicine Foundation, United States
- Welsh Association of ME & CFS Support (WAMES), United Kingdom

The autoimmune virus? ground-breaking EBV finding could help explain ME/CFS

Source: http://simmaronresearch.com/2018/04/autoimmune-virus-groundbreaking-ebv-finding-help-explain-mecfs/
By Cort Johnson 30th April 2018

> "I've been a co-author in almost 500 papers. This one is more important than all of the rest put together. It is a capstone to a career in medical research," Harley

I sensed some awe in Ron Davis's voice as he pushed for more understanding of Epstein-Barr Virus's effects in ME/CFS during a talk at the Brain Science conference. Davis is not to my knowledge finding much evidence of EBV reactivation in the severe ME/CFS patient study – a surprise – but he is very interested in what happened during that initial EBV infection, which appears to have triggered chronic fatigue syndrome (ME/CFS) in so many people.

He's not alone in his "admiration" for the virus. Simmaron's Advisor, Dr. Daniel Peterson, whose clinical practice and research stemmed from an outbreak in the Lake Tahoe region of Chronic Fatigue Syndrome, has tracked EBV in patients for decades, noting very high titers to EBV and other herpes viruses in subsets of patients.

It's not surprising that these two important figures have had their eyes on EBV. EBV, after all, is kind of in a league of its own. An invader of B and epithelial cells, the 50th anniversary of its discovery was recently celebrated with numerous reviews. Epstein-Barr was discovered in 1966 by Anthony Epstein and Yvonne Barr. It was the first human virus shown to cause cancer. The sequencing of its large genome in 1995 helped launch the genomic era.

One of the more massive and complicated viruses, it's one of the very few viruses that's able to avoid elimination: once EBV infects your B-cells, it's in your body to stay. It's able to effectively hide from the immune system and reactivate just enough so that when the infected B-cells die it can move on to other cells.

We're well equipped to ward off EBV when we're young – it usually produces only minor symptoms – but as our immune systems alter as we age, that changes. Encountering EBV as an adolescent or adult (infectious mononucleosis, glandular fever) – as increasingly happens in our germ phobic age – often means months of convalescence as our immune systems struggle to ward off this powerful virus.

The problems don't stop there. We know that infectious mononucleosis (IM) is a common trigger of ME/CFS but coming down with IM/glandular fever in adolescence has also been shown to increase one's risk of coming down with multiple sclerosis 2-4 fold and lupus by fifty percent. Because of EBV's ability to remain latent in the body, EBV reactivations are a huge problem for transplant patients with compromised immune systems.

The big question concerning EBV is how a virus which has essentially been latent for decades could contribute to serious diseases like MS and lupus. We now may have the answer. Last week, what will probably turn out to be a seminal paper in pathogen research directly showed for the first time how EBV appears to be able to trigger autoimmune diseases later in life and could conceivably play a role in ME/CFS.

The rather hum drum title of the paper "Transcription factors operate across disease loci with EBNA2 implicated in autoimmunity" in the Nature Genetics Journal hardly hinted at the possibilities the paper presents.

EBV consists of several proteins of which EBNA-2 is one. EBNA-2 is EBV's main viral trans-activator; i.e. it's a transcription factor that turns on genes in an infected cell that help EBV to survive. Essentially EBNA-2 allows EBV to hijack a cell's genetics and put them to its own use.

The study – produced by researchers at Cinncinnati's Children Hospital – demonstrated that once EBV infects B-cells, it turns on genes that have been identified as risk factors for a boatload of autoimmune diseases.

It turns out that even though the virus is, so to speak, latent; i.e. it's not replicating – its transcription factor is still active – altering the expression of our genes. The genes that it affects just happen to be the same genes that increase the risk of developing lupus, multiple sclerosis (MS), rheumatoid arthritis (RA), juvenile idiopathic arthritis (JIA), inflammatory bowel disease (IBD), celiac disease, and type 1 diabetes. Apparently decades of genetic assault from EBV's transcription factor can set the stage or at least contribute to many autoimmune diseases.

Chronic diseases are usually caused by a variety of genetic and environmental factors. Because not everyone with these transcription factors comes down with a chronic illness, other factors must play a role. The authors believe, though, that the gene expression changes induced by the virus in the B cells could account for a large number of people with lupus and MS who fall ill.

> "In lupus and MS, for example, the virus could account for a large percentage of those cases. We do not have a sense of the proportion in which the virus could be important in the other EBNA2-associated diseases," Harley

Chronic Fatigue Syndrome and EBV/Infectious Mononucleosis – A Short History
Researchers have been trying to figure out – mostly unsuccessfully- what the heck happens to plunge people with infectious mononucleosis into ME/CFS for quite some time.

Infectious mononucleosis/glandular fever is believed to be a common trigger of ME/CFS
In fact, infectious mononucleosis/glandular fever was probably the first disease associated with ME/CFS. Studies in the mid-1990's, including one from the CDC, suggested ME/CFS was, at least in part, "chronic infectious mononucleosis" or "chronic mononucleosis syndrome". Even Stephen Straus penned a paper on the "The chronic mononucleosis syndrome".

Straus's small 1989 study reporting high rates of psychiatric diagnoses in ME/CFS patients prior to their becoming ill set a theme in motion which was disproved by two Peter White ME/CFS IM publications. White found IM/glandular fever to be a particularly strong trigger of ME/CFS which he concluded was probably responsible for about 3,000 new cases of ME/CFS a year in the U.K.

A 1992 Swedish study began a trend of examining people with ME/CFS during infectious mononucleosis and afterwards in order to try and determine what happened. That study concluded that whatever happened was not due to EBV reactivation.

In 2010 Taylor found reduced peak oxygen consumption during exercise in adolescents with ME/CFS after IM compared to IM patients who had recovered. Broderick's finding of altered cytokine networks associated with Th17 in ME/CFS patients following IM suggested immune dysregulation had occurred.

Glaser's 2005 study suggested that an EBV encoded enzyme produced by a non-replicating form of EBV could be producing symptoms in ME/CFS. Lerner's 2012 study suggested that antibodies to two EBV produced proteins were commonly present in ME/CFS – suggesting that a prolonged immune reaction to EBV might be occurring in ME/CFS as well.

In 2014 Loebel/Scheibenbogen suggested that ME/CFS patients may be having difficulty controlling the early stages of EBV reactivation. Loebel's 2017 follow up study suggested that ME/CFS patients' immune system might be over-reacting to an EBV produced protein and that autoimmunity might be involved.

Leonard Jason's large IM college student study will hopefully provide clues why some people never recover from it. He's completing data analysis of a study examining college students who came down with infectious mononucleosis and then ME/CFS. So far Jason has found that at least 4-5% of college students come down with IM while at school.

Treatment implications
Interestingly, several drugs that are available can block some of the transcription factors EBV has inserted into B-cells. (I was unable to determine what they are.) The authors also hope the study will help spur more efforts to produce an EBV vaccine.

Next for ME/CFS and EBV
Now that we have evidence that EBV/IM contributes to many autoimmune diseases, it's hard to think that ME/CFS is not somehow involved. Chronic fatigue syndrome is different in that infectious mononucleosis (and other infections) immediately triggers ME/CFS in many people. What we don't know is if bouts of IM also trigger ME/CFS 5, 10, 15 or more years later as occurs in these other disorders.

Opportunities for collaboration open up
The big question awaiting ME/CFS now is if the abnormal transcription factors associated with the autoimmune diseases in the recent paper are present. The good news is that a study determining that appears to be within reach of an ME/CFS researcher with the technical ability and funds. In an unusual move, the Cincinnati researchers are making the computer code they used available to other researchers.

"We are going to great lengths to not only make the computer code available, but all of the data and all of the results. We think it's an interesting approach that could have implications for many diseases, so we're contacting experts on the various diseases and sharing the results and seeing if they want to collaborate to follow-up on them." Weinrauch

> "This discovery is probably fundamental enough that it will spur many other scientists around the world to reconsider this virus in these disorders" Harley

They believe EBV will be implicated in many more diseases, and there is already some evidence that it is. Using the same analytical techniques, they've already identified 94 other diseases including many non-autoimmune diseases in which EBV may play a role.

This is one of the few studies in which the researchers are so jazzed by their results that they've dropped all pretences to modesty. The study results need to be validated, but because EBV is so common and is potentially linked to so many autoimmune (and other diseases), it has the potential to rewrite our understanding of how autoimmune diseases arise. The authors fully recognize the potential importance of their finding. The lead author of the study, John Harley, said:

> "I've been a co-author in almost 500 papers. This one is more important than all of the rest put together. It is a capstone to a career in medical research," Harley

One of the senior authors of the study stated:

> "This same cast of characters is a villain in multiple immune-related diseases. They're playing that role through different ways, and doing it at different places in your genome, but it's the same sinister characters. So if we could develop therapies to stop them from doing this, then it would help multiple diseases." Matthew Weirauch

#MillionsMissing

Source: www.meaction.net/2018/05/16/the-global-impact-of-millionsmissing

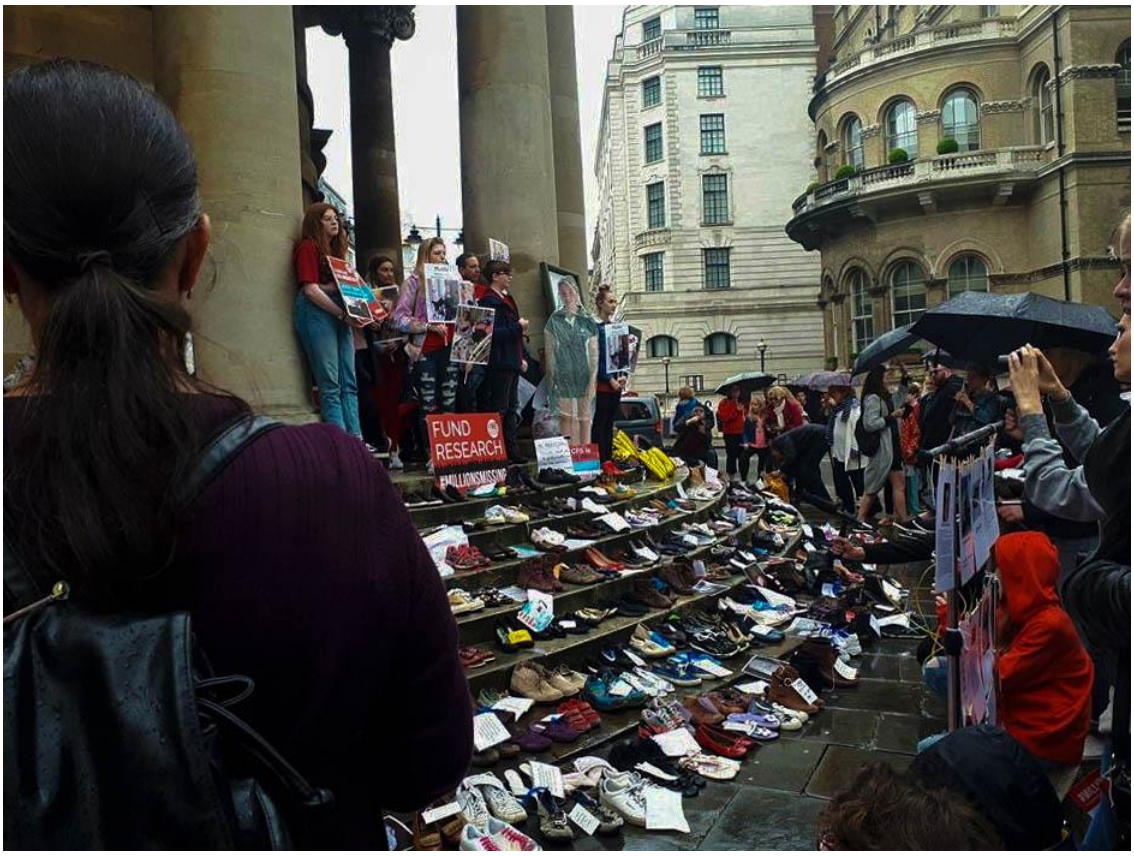
If on May 12th, you find yourself out and about in Amsterdam, Boston, London, Chicago, Edinburgh, or one of approximately 95 other cities around the world, it is likely that you will encounter a plaza or other outdoor area populated with pairs of shoes. At first glance you may assume that you have stumbled upon the scene of some conceptual or performance art, but the uninhabited footwear is intended to catch the eye of passers-by—and the world—as part of #MillionsMissing, a global campaign including a series of in-person and virtual advocacy events meant to call attention to the millions of people around the world suffering from Myalgic Encephalomyelitis.

The impact of #MillionsMissing 2018 was phenomenal. Protestors took to the streets in 100 countries across the world with demonstrations taking place in North America, South America, Europe, the United Kingdom, South Africa and Asia. Along with people taking action from home, there was a total of 300 visibility actions. More than 50 news organizations ran stories about the plight of people with ME. The #MillionsMissing hashtag trended on Twitter.

United Kingdom

The #MillionsMissing had demonstrations, rallies, and visibility actions in 29 locations, from Birmingham to Edinburgh, London to Southampton. Edinburgh hosted Stuart Murdoch, lead singer of Belle and Sebastian who has ME, and had the 'flash mob' Sing in the City perform. They ended with a "massive lie-down" to represent those incapacitated by ME. Sheffield was bright with art and music, featuring performances from dancers and musicians. St. Helen's showed us what just a few people with an indomitable spirit can accomplish.

In Newry in Northern Ireland, #MEAction and Hope for ME & Fibro joined forces. Unrest was shown at Newry City Hall, and a discussion with a panel of experts was held afterward. And in Southampton, a massive array of shoes were displayed in a town square, "reminiscent of war graves."



On the steps of the BBC Broadcasting House in London

Europe
Creative displays and music were a huge part of the European #MillionsMissing actions. Bielefeld, Germany had an illness imitation suit to give people an idea of what it would be like to have ME. Berlin featured dance, and five tele-avatars from No Isolation to bring bedridden pwME to the event. Sweden was filled with song and Norway had partner support from Norway's ME society. A lot of institutions supported the efforts of #MillionsMissing in Prague, Czech Republic. Doctor Olli Poli gave a speech in Helsinki, Finland, and in Amsterdam #MillionsMissing opened the stock exchange!

In Châteaubourg, France a member of parliament, mayor, and several members of local municipality council joined #MillionsMissing. Switzerland hosted an international visibility action!

Members of Fanclub Gruppa Süd in Berlin unfurl a "Can you see ME now?" banner

United States
In the United States, there were actions that spanned the country: from large events in Washington DC, Minneapolis, New York, Chicago, Atlanta, Boston, Los Angeles, and San Fransisco, to small but mighty actions in Eau Claire, Marietta, Morristown, Denver, and Honolulu. An amazing #MEAction volunteer hosted a moderated virtual event that invited homebound people to come together!

Annette Gaudino of Treatment Action Group, Jim Eigo of ACT UP, and actress Amy Carlson gathered at the front of Central Park in New York. Partners like Linda Tannenbaum from Open Medicine Foundation joined over 80 participants in Los Angeles, CA. SMCI's Carol Head joined the Washington, DC #MillionsMissing before SMCI's Advocacy Day on Capitol Hill. Ron Davis and Janet Dafoe spoke in San Fransisco in honor of their son, Whitney. Cities across the United States honored Whitney in a plea to ask Francis Collins to find a cure. In LA, Omar Wasow held up an iPad as Jennifer Brea, co-founder of #MEAction and director of Unrest, spoke from bed. Musicians played across the country alongside large shoe displays. Tucson's event included stand-up comedy, a band, and a proclamation from the mayor! Atlanta's demonstration demanded attention with art and made a statement in front of CNN headquarters.

Please refer to the source link at the start of this article for more information…

Inquest ruling: young drama student Merryn Crofts lost her life to M.E.

Source: www.meassociation.org.uk/2018/05/inquest-ruling-young-drama-student-merryn-crofts-killed-by-m-e-18-may-2018

Merryn, from Rochdale, today (18th May) became only the second person in the UK to have M.E. – myalgic encephalomyelitis – listed on a death certificate.

Merryn's mum, Clare Norton, sobbed as she told Rochdale Coroner's Court how her "beautiful" and "energetic" daughter was left wheelchair-bound and reliant on tube feeding.

In August 2011, Merryn, then 15, was diagnosed with hives and swelling shortly after coming back from a family holiday in Mallorca.

Tests in early 2012 revealed that at some point she had contracted glandular fever – a virus which can trigger M.E.

Despite dozens of medical appointments – including mental health checks for panic attacks – Merryn's condition deteriorated as she suffered breathing problems, exhaustion and excruciating hypersensitivity to touch, light and sound.

She was eventually diagnosed with M.E. in the summer of 2012.

The would-be theatre star, who was forced to wear an eye mask, also suffered from severe migraines, brain fog, slurred speech and persistent infections.

Stomach problems, and problems swallowing, meant that her weight plummeted to just five-and-a-half stone.

Coroner Katherine McKenna was told that Merryn could take on just 100 calories a day because her gut was in so much pain, and that, by 2015, even two teaspoons of nutrients were intolerable.

Merryn was eventually fitted with an intravenous nutrition line but suffered intestinal failure and was given a terminal diagnosis in 2016.

She died on May 23, 2017, just days after her 21st birthday.

Source: www.hfme.org/medeaths.htm

Dr Elizabeth Dowsett (1920 – 2012) a genuine hero for M.E. patients, studied medicine at Edinburgh University, working first as a GP and then as a microbiologist. She began to focus on M.E. in the 1960s and went on to work with leading M.E. experts then and now, Dr Ramsay and Dr Richardson, and to see thousands of patients with M.E. Dr Dowsett's high quality work saw her became one of the most experienced and knowledgeable M.E. experts in the world. Her papers on M.E. are still relevant and essential reading today for patients and doctors.

Dr Elizabeth Dowsett estimates the death rate for M.E. to be roughly 3%. There are deaths due to cardiac failure, brain death, tumours, and liver failure. All kinds of deaths. There are sudden deaths following exercise/overexertion, and deaths which occur after a long period of slowly worsening illness. Dr Dowsett states, '20% have progressive and frequently undiagnosed degeneration of cardiac muscle which has led to sudden death following exercise.' Dr Dowsett explains that although these deaths are due to M.E., they are disassociated from it, and are almost never recorded in statistics as deaths from M.E.