25 Years
1993 – 2018

REMEMBERING 25 YEARS ……

Dear Friends:

First of all, I am writing the Fall issue of QUEST because our President, Margaret Parlour, who normally does it, is on a much-needed and deserved vacation. Margaret worked very hard for the May Conference 2018, in addition to her regular commitments. Thank you, Margaret, and also a special thank you to our Director of Special Projects, Anne Marie MacIsaac, who also worked hard not only on the Conference but also is a whiz at making our newsletter look so professional.

This year, on June 18, 2018 it has been 25 years since the founding of the National ME/FM Action Network and looking back over the years, it is satisfying to know that we are in an active race to find answers for ME/FM but that we also are not alone anymore. There now is a genuine interest in research and we no longer have to keep pointing out that ME/CFS and FM are real illnesses, but also very debilitating.

Although the perception has changed, we are by no means in an easier position to get what we need and what is pushing us forward is the united front our ME/FM community has established by not taking "NO" for an answer nor will we ever accept it.

There is a danger of us personally getting lost in the shuffle which a doctor visit can do to you with an unkind and insensitive remark, or by a friend who thinks you're disloyal because yet again you had to cancel another get-together.

I realized how important the ME/FM community is to all of us. It is not only for keeping up with medical and research data but also to make us visible to ourselves. By reading others' stories, it confirms in us that yes, it is real. I am not imagining these symptoms. By being accepted as we are and not questioned about the legitimacy of our ill health, it reaffirms in us that we are not alone and there are those who not only understand but care about us.

It is important to all of us to support each other as we go through the many daily struggles we are going through and don't become dismissive of ourselves by thinking we are invisible. That is only to the untrained eye and to those who didn't care enough to educate themselves on your illness.

I get often asked what I would do differently about my illness, if I knew then what I know now. I have made kind of a list, not necessarily in the right order for anyone else but a list none the less.

1. BELIEVE in yourself. If you have a pain or any symptom, then that is what you have;
2. BE your own driver. Don't let anyone steer your wheel when they are steering you in the wrong direction;
3. When you think you have come down with a flu or similar condition, if it doesn't go away after a short period of time, get it checked out immediately;
4. GET another opinion, if your doctor plays down your symptoms and doesn't give you the support you need;

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5. DON'T worry about whether the doctor will think you are wasting his time. You are worth it and deserve their attention;
6. WHEN you apply for sick benefits and you get refused, see a lawyer immediately. Look for a lawyer who will do the first consultation for free. At this early stage, sometimes only a letter from a lawyer is all you need to get your benefits;

I can only stress again how important it is that you steadfastly believe in yourself. You are managing your life and on the days you feel you can't go on, hold on to the fact that you are not alone.

Sincerely,

NATIONAL ME/FM ACTION NETWORK

Lydia

Lydia E. Neilson, MSM

CEO, Founder

CFS/ME International Conference 2018

GRIFFITH UNIVERSITY

National Centre for Neuroimmunology and Emerging Diseases

RID: Research Innovation & Discovery

AT: Crowne Plaza Surfers Paradise

Queensland

AUSTRALIA

Date: November 26-27, 2018

[Earlybird Registration Deadline – October 15, 2018]

https://www.griffith.edu.au/griffith-health/events/ncned-cfsme-2018

Important Announcement on Canada Pension Plan – Disability (CPP-D)

Dear friends

On August 27, 2018 (the Government of Canada introduced a new application form and a new medical report form for CPP-D.

[For the time being, an application may be submitted on either the old or the new forms though there may be some difficulty finding the old forms on-line.]

The National ME/FM Action Network has NOT had the opportunity to look at the new forms in detail or to update our CPP-D Applications and Appeals Guide.

Nevertheless, our Guide will still be highly relevant to people applying for CPP-D. It recommends that people think about:

1) their symptoms,
2) the effect that their symptoms have on their activities, and
3) the impact that their activity limitations have on their ability to work.

This is very much the underlying model of the new application form.

We would be interested in hearing your comments on or experiences with the new form.

Our Guide can be found here:

http://www.mefmaction.com/index.php?option=com_content&view=article&id=425&Itemid=364

The new forms can be found here:

https://catalogue.servicecanada.gc.ca/apps/EForms/pdf/en/ISP-1151.pdf

Sincerely,

NATIONAL ME/FM ACTION NETWORK

Margaret Parlor, President

SAGE journals

Journal of Health Psychology

Confirmatory factor analysis of myalgic encephalomyelitis and chronic fatigue syndrome stigma scale

By: Terman et al

First published September 5, 2018

554 international individuals with ME or CFS completed the stigma scale which left no doubt that there is a high level of stigma, estrangement, and disclosure and what these findings implicate.

Open to those with a SAGE account, Institutional Access or purchase article.

http://journals.sagepub.com/doi/abs/10.1177/1359105318796906?journalCode=hpqa

New Norwegian Study Suggests CDC IOM ME/CFS Diagnostic Criteria Tend to Select Patients with Depressive Symptoms

Author, Jerrold Spinhirne, in his June 7, 2018 article states that the Centers for Disease Control and Prevention (CDC) adopted the new diagnostic criteria developed by the Institute of Medicine (IOM) and renamed the National Academy of Medicine, has adopted the IOM diagnostic criteria to replace the previous 1994 Fukuda CFS research definition. The CDC is calling it ME/CFS.

The new IOM criteria are to be used for ME/CFS and the 2015 IOM report calls “Systemic Exertion Intolerance Disease” (SEID). The CDC adopted the IOM SEID diagnostic criteria before it had been validated by independent research. Research done by DePaul University rather than validating the IOM criteria suggests that the four required SEID symptoms are commonly reported by patients with a variety of medical and psychiatric disorders and a new Norwegian study shows evidence of the unfitness of the new CDC SEID criteria.

To see study and more details, please go to:
http://bmjpaedsopen.bmj.com/content/2/1/e000233

To see author Spinhirne’s article, please go to:

https://www.facebook.com/notes/jerrold-spinhirne/new-norwegian-study-suggests-cdc-iom-mecfs-diagnostic-criteria-tend-to-select-pa/2049418745129694/

The Canadian Press

[article updated June 6, 2018]

By: CAMILLE BAINS - Vancouver

The College of Physicians & Surgeons of British Columbia have revised the existing standard of practice and making it more clearer to doctors about their obligation to properly assess and document discussions about dosage, tapering and stopping the drugs if necessary.

"Physicians cannot exclude or dismiss patients from their practice because they have used or are currently using opioids. It's really a violation of the human rights code and it's certainly discrimination and that's not acceptable or ethical practice."

The new requirements came about after widespread consultations of doctors in the province and patient advocacy groups who complained that people were denied care or abandoned because they were on opioids.

For complete article, please go to:

https://www.theglobeandmail.com/canada/article-bc-doctors-cant-limit-opioids-or-discriminate-against-pain-patients-2/

Having your Back against the Wall

Good and Bad Exercises for Low Back Pain - WebMD

Issues that people with ME/FM face is lower back pain. At any get-together, you look around the room and you see people leaning against the wall or using the back of chairs as support to take the pressure off their back and save energy.

I used to think that it was standing up that is tiring which of course is true but in our case it is exaggerated by the pressure on our lower back. Even doing small tasks inevitably leads to pressure on the lower back, forcing someone to sit down.

On WebMD there is a section on good and bad exercises that are least invasive for those with lower back pain. There are illustrations shown and of particular interest is No. 7 as it is just standing with your back against the wall and slowly sliding down to half-way position.

https://www.webmd.com/back-pain/ss/slideshow-exercises

What's Up @ CIHR?

[Canadian Institutes of Health Research]

News releases

June 13, 2018 – Ottawa, Ontario – CIHR

A new Collaborative Health Research Projects competition has been launched with the goal of bridging artificial intelligence, health research and, for the first time, the social sciences and humanities. The aim is to use a "fresh approach" to research funding encouraging greater collaboration across disciplines leading to new medical practices and technologies. More than $24M has been put aside, with $6 Million being reserved for investigating the ethical, legal and societal impacts associated with artificial intelligence through the health sector.

Thirty research teams from across Canada will be receiving more than $20M to address issues such as vision loss, Alzheimer's, heart disease, and cancer. Through their collaborations, it will lead to new inventions and therapies to put into the hands of Canadian doctors and nurses who are in the front lines of treating patients.

This Collaborative Health Research Project program unites the CIHR, the Natural Sciences and Engineering Research Council (NSERC) and the Social Sciences and Humanities Research Council of Canada (SSHRC) to bring cutting-edge science to the front lines of health care.

https://www.canada.ca/en/institutes-health-research/news/2018/06/canadas-scientists-can-pitch-projects-that-bridge-artificial-intelligence-health-research.html

June 20, 2018

The Minister of Health appointed Dr. Michael J. Strong as the new President of CIHR, commencing October 1, 2018. Dr. Strong is an internationally recognized researcher specializing in ALS (amyotrophic lateral sclerosis) known as Lou Gehrig's disease.

Dr. Strong has served since 2010 as the Dean of the Schulich School of Medicine & Dentistry and Distinguished University Professor at Western University.

From 2000 to 2010, he served as Chief of Neurology and Co-Chair in the Department of Clinical Neurological Sciences at the London Health Sciences Centre and Western University. Dr. Strong's research focuses on understanding the cellular biology of ALS.

CIHR's Budge 2018 proposed the largest increase in new funding for fundamental research and the Budget set aside dedicated funding to support researchers working across disciplines and with international collaborators.

Biography of Dr. Michael J. Strong

Please go to:

https://www.canada.ca/en/institutes-health-research/news/2018/06/biography-of-dr-michael-j-strong.html

July 24, 2018

CIHR through an investment from the Government of Canada and a number of provincial and internationals partners and research institutions will allow scientists to test-drive new ways to treat disease and improve patient care.

Member of Parliament, Sonia Didhu, on behalf of the Minister of Health, announced that CIHR will allot $9.3 Million to St. Michael's Hospital where three research projects will be based. Known as the Innovative Clinical Trials Initiative, additional funding of $13.3 Million from partners will also be invested. This will provide support over four years to seven projects:

- Reducing the incidence of diabetic foot issues;
- Reducing the number of unnecessary x-rays and pre-operative tests administered to patients;
- Supporting doctors to improve opioid- and antibiotic-prescribing practices;
- Reducing childhood obesity;
- Improving care and outcomes for intensive care units;
- Helping patients with multiple complex conditions; and
- Improving care and recovery for young adults with psychosis.

For details, please go to:

https://www.canada.ca/en/institutes-health-research/news/2018/07/health-researchers-test-drive-the-promising-new-treatments-of-the-future-with-support-from-the-government.html

For Funding Decisions Data Base information, please go to:

http://webapps.cihr-irsc.gc.ca/decisions/p/main.html?lang=en

For 2018 Funding Decisions Notifications, please go to:

http://www.cihr-irsc.gc.ca/e/196.html

July 27, 2018

Canada Research Coordinating Committee launches consultation [CRCC]

The CRCC is launching a national consultation to reinvigorate Canada's support for science and to position Canada as a global leader in research excellence.

The online consultation portal was live and was focussed on 3 priorities:

1. Creating a new tri-agency fund to support international, multidisciplinary, high-risk and rapid-response research that generates new knowledge;
2. Strengthening equity, diversity and inclusion in research; and
3. Supporting early career research.

Budget 2018 proposed to invest more than $1.7 billion over five years to support researchers through Canada's granting councils and research institutes. This includes $275 million over five years to support the new Tri-Agency Research Fund. Stakeholders are invited to provide feedback on a draft funding model that the CRCC has developed to ensure we maximize the positive impact on academic research in Canada.

Consultations were held in communities across Canada. Input from this process will inform the development of a call for proposals this fall for the tri-agency fund.

The CRCC was created to improve the coordination efforts of Canada's granting agencies - the Social Sciences and Humanities Research Council of Canada, the Natural Sciences and Engineering Research Council of Canada, and the Canadian Institutes of Health Research - as well as the Canada Foundation for Innovation.

To view entire article, please go to:

http://www.cihr-irsc.gc.ca/e/51107.html

For Canada Research Coordinating Committee Mandate & Work Plan, please see:

http://www.cihr-irsc.gc.ca/e/51107.html

M.E. Research Conference Report: London, U.K. June 1, 2018

[Invest in ME Research (IMER) Conference]

IMER summarized Dr. Shepherd's 13-page report on the conference, as follows:

For those who wish to go further, in addition to Dr. Shepherd's summary are the links to more detailed reports.

Dr. Charles Shepherd, who is the honourable Medical Adviser of the U.K. ME Association, summarized key points that came out of the 2018 conference.

Chaired by Dr. Ian Gibson, the audience was made up of caregivers, charity representatives, health professionals and researchers from the UK and overseas.

Speakers:

Dr. Beth Unger, Chief of Chronic viral Diseases Branch of the Centres for Disease Control & Prevention (CDC), USA spoke about three research studies the CDC are involved in: cardiopulmonary testing, cognitive function and NK cell function. This is presently in progress and is called the NASA lean test.

Dr. Vicky Whittemore, Programme Director at the National Institute of Neurological Diseases and Stroke, National Institutes of Health (NIH), USA stated that the NIH are involved in a number of ME/CFS initiatives.

DrAvindra Nath, Head of Infections of the Nervous System at the National Institute of Neurological Diseases and Stroke, National Institutes of Health (NIH), USA. Dr. Nath is leading an internal research study "looking in great detail" at people with ME/CFS who have a clear infectious onset to their illness and in the early stages of illness.

During the question and answer section of his presentation, he was reluctant to go as far as saying that NIH regarded/ classified ME/CFS as a neurological disease but that it needed to be investigated.

PhD students from the Quadram Institute of Bioscience, Norwich: Role of the gut microbiome in ME/CFS. The students outlined the theory that the viral and bacterial organisms that inhabit a healthy digestive system may change to either cause or be involved in non-gastrointestinal disease.

Dr Kristian Sommerfelt, Haukeland University Hospital, Bergen, Norway; a clinical presentation on Myoclonic jerks.

DrSommerfelt, sees about 20 to 25 ME/CFS patients per year and described some of the cases he has dealt with and stated that about 80% of the patients he had studied experienced sudden solitary and unilateral (one sided) jerks in the hand and foot,

Dr Peter Johnsen, Internal Medicine, University Hospital of North Norway, Harstad, Norway: Double-blind, single centre, placebo-controlled, randomised clinical trial treating ME/CFS with faecal microbiome transplantation (FMT).

The normal purpose of FMT is to replace good bacteria that has been killed or suppressed, usually by the use of antibiotics, causing bad bacteria – specifically Clostridium difficile – to over-populate the colon.

Professor Karl Tronstad, Cellular Energetics, Department of Biomedicine, Haukeland University Hospital, Bergen, Norway: Cellular energetics.

Professor Tronstad and his group already had reported on changes in the amino acids and gene regulation that are consistent with altered regulation of the central enzyme pyruvate dehydrogenase in people with ME/CFS and how serum changed energy metabolism in healthy muscle cells in culture..

Dr. Tronstad also reported that some of the research findings suggest abnormalities in the way glucose is broken down. A study being funded by the Norwegian Research Council will investigate further the role of defective energy metabolism in ME/CFS.

Professor Don Staines, National Centre for Neuroimmunology and Emerging Diseases, Griffiths University, Queensland, Australia.

Don Staines summarised the possible role of abnormalities in calcium ion channels in ME/CFS, and some of the immune system research on natural killer (NK) cell function that is being carried out by the researchers at Griffiths University in Australia.

Professor Theoharis Theoharides, Professor of Pharmacology and Internal Medicine, Tufts University, Boston, USA: The Anne Ortegren Memorial Lecture on mast cell disease and ME/CFS.

Professor Theoharides has an interesting hypothesis that

stimulation of the mast cells in the hypothalamus activates microglia leading to the secretion of pro-inflammatory cytokines that disrupt normal physiological mechanisms and have an adverse effect on mitochondrial function.

Associate Professor Mady Hornig, Centre for Infection and Immunity, Columbia University Mailman School of Public Health, New York, USA.

Professor Hornig's research is on establishing immune system profiles in ME/CFS and identifying infections that may be linked to the disease and relating to increased levels of some pro-inflammatory cytokines.

Professor Maureen Hanson, Director, Department of Molecular Biology and Ge Mady Hornig's research is on establishing immune system profiles in ME/CFS and identifying infections that may be linked to the disease and relating to increased levels of some pro-inflammatory cytokines.

Professor Hanson described the NIH Collaborative Research Centre (CRC) studies on an exercise challenge test with ME/CFS people using two cardiopulmulmonary exercise tests with a protocol developed by Workwell College and Dr. Betsy Keller at Ithaca College.

Professor Markku Partinen, University of Helsinki, Finland.

Professor Partinen gave a presentation covering both the role of sleep and what we know about sleep abnormalities in ME/CFS.

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

Professor Ron Davis, Professor of Biochemistry and Genetics at Stanford School of Medicine, Stanford, CA, USA: Revolutionising biomedical research through technology development.

Professor Davis updated on all the ME/CFS research taking place at Stanford and as part of the Open Medicine Foundation and reported progress in analysing the data from a severely ill patient study and noted a considerable number of mutations common in ME/CFS patients.

Please see link below for more particulars:

http://www.meassociation.org.uk/wp-content/uploads/Dr-Shepherd-IiMER-Conference-Report-2018-13.06.18.pdf

HealthRising:

Dynamic Duo: Lucinda Bateman and Ron Davis Rock the Brain science Conference

By: Cort Johnson

It seemed like a dicey thing – a talk on chronic fatigue syndrome (ME/CFS) that seemingly had little to do with the conference. The Brain Science Conference is a small conference series which began in 1990 and has been going ever since. Its goal is basically to provide brain researchers with a diverse set of talks on their field.

The 2018 Brain Science Conference was held in beautiful Sedona, Arizona

Mixed in amongst the talks on Parkinson's, Epilepsy, neurotoxins, pain circuits and neurodevelopment was a session simply titled "Chronic Fatigue Syndrome". The two talks: "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): a multisystem illness invisible in plain sight", by Lucinda Bateman, MD; and, "Developing new technologies to unravel chronic fatigue syndrome", by Ron Davis PhD, didn't even pretend to make an explicit connection with brain science. I wondered how many people would show up and how the talks would be received. I readied myself for a paltry turnout but the small conference room was full.

How the Brain Science Conference had managed to insert a session on the basics of chronic fatigue syndrome (Dr. Bateman) and innovative tools for understanding it (Ron Davis) was a mystery to me, until, that is, I talked to the person sitting next to me. I'd snuck into the conference. I was camping out in Flagstaff when Janet Dafoe, Ron's wife, informed me that Ron was going to be speaking on ME/CFS that weekend in Sedona – just an hour away.

After asking if I could attend the session, Ron said he thought I could probably sneak in – so I did. Furtively sitting at a table in the corner, I looked to the right to find a woman staring at me. Who are you, she said? It turned out she was the conference organizer and she was happy to have me there.

I was certainly happy to be there. It was a treat listening to these pros.

Dr. Bateman: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): a multisystem illness invisible in plain sight

"These patients are trapped inside of a body that isn't working".

Dr. Bateman started by bluntly stating, "I'm here to get all of you to start thinking of this illness". She aimed to give them a talk they would remember — and she did. First, she hit them between the eyes with one of those chronic fatigue syndrome stories that could keep one up at night.

She took them back to 1979 to a young woman on a high school cross country team who had taken time off to heal from a stress fracture. Her stress fracture healed, but her body mysteriously fell apart. Instead of leaving her stronger, running left her fatigued, nauseous and prone to vomiting. By her senior year in the early 1980's – well before chronic fatigue syndrome even had a name in the U.S. – she'd had to abandon all physical exercise.

Dr. Bateman – the head of the Bateman Horne Center in Salt Lake City gave a powerful presentation on the clinical side of ME/CFS

She struggled on and was able to complete her college degree and become a preschool teacher, but had trouble maintaining a regular work schedule. A severe respiratory illness triggered problems with insomnia that continue to this day. On one of her many attempts to figure out what the heck was happening to her, she was misdiagnosed with schizo-affective disorder.

As time went on, she got worse and worse. By the time she saw Dr. Bateman, our former runner and teacher had trouble reading and comprehending the printed word on her worst days. It took only a few simple tests to indicate that her autonomic nervous system had gone haywire. Upon standing, her heart rate zoomed from 67 to 130, while her pulse pressure (the difference between systolic and diastolic pressure) dropped from a normal 61 to a decidedly low 29.

According to Wikipedia, a pulse pressure of 25 mmHg or less signifies either congestive heart failure or cardiogenic shock. It's usually associated with significant blood loss due to trauma (aka a significant injury). In ME/CFS, it probably just reflects extremely low blood volume. Remarkably, this woman – who could hardly stand without her system collapsing – had had a tilt table test before seeing Dr. Bateman but was told it was negative because she hadn't passed out. A cardiopulmonary exercise test of this former runner indicated that her VO2 max was now 16 – 25% of normal.

Compression socks, midrodrine and propanolol helped, but even with these therapies she still meets the criteria for postural orthostatic tachycardia syndrome (POTS). At 37, she can manage about 4-6 hours upright – not standing upright but sitting upright. Over half her life has now been spent ill.

Dr. Bateman moved onto some key characteristics of the disease. There's the inability to reproduce energy production after an exercise challenge – still probably the most startling study result ever found in ME/CFS. It's a result that goes to the core of this disease. After showing that result to a guru of exercise physiology, Dr. Bateman reported he said, "If that's true then it's unique". Yet, that finding has actually been demonstrated in studies containing 51 patients, 22 patients, 15 patients and six patients – but apparently not yet to the guru's satisfaction.

Over ten years since this finding appeared, we still lack the definitive study that would prove to him and others that something has gone badly awry with energy production and exercise in ME/CFS. Why that study hasn't been done is a mystery to me. It would also explain ME/CFS in simple, basic terms that everyone could understand.

My view is that the best way to wake up the research community to the seriousness and uniqueness of this disease would be with a large, rigorously controlled, two-day exercise study that irrevocably demonstrated the presence of a unique energy deficit in chronic fatigue syndrome (ME/CFS).

Dr. Bateman highlighted the weird sleep problems in ME/CFS – the high alpha waves at a time they should be low, and the low delta waves at a time they should be high). (ME/CFS patients brains are in sleep mode when they are awake, and in awake mode when they're asleep.) She suggested that central sensitivity may be responsible for a lot of the sleep problems in ME/CFS.

Continuing with this theme, Dr. Bateman talked about the "wired and tired" issues, the too-exhausted-to-sleep problems and the over-signaling; i.e. the unrelenting brain activation that leaves the brain highly sensitive to any kind of stimuli and keeps it from settling down, resting and rejuvenating.

That shows in the sympathetic overdrive and the

increased heart rates during sleep and the reduced heart rate variability. With the loss of HPA axis stability comes problems with circadian rhythms.

Dr. Bateman suggested that central sensitization could be responsible for many of the sleep problems in ME/CFS

Spitting out some eye-opening statistics – the disease affects from 800,000 to 2 million Americans, is responsible for $17-24 billion in economic losses yearly but is undiagnosed in 80% of patients, is not taught in medical school, and gets about $13 million in funding from the NIH - Dr. Bateman asked: how on earth does a disease this common and this serious get overlooked?

She asserted that part of the problem is just the way our medical system works. By and large, the U.S. medical system is not concerned about viruses – which triggers many people's illnesses – and has a rudimentary understanding of the immune and endocrine system. Cellular metabolism – possibly a very big deal in ME/CFS – is hardly on its radar at all.

That said, Dr. Bateman said that she firmly believed that early diagnosis and proper early treatment could change the prognosis for many. She also believes that we know 90% of what we need to know about ME/CFS and if we could get more cross-talk across specialties going, we could figure this thing out. On that positive note, Ron Davis came in.

Dr. Ron Davis: Developing new technologies to unravel chronic fatigue syndrome

Davis provided a different tack. Describing the technologies his lab is developing that may be helpful in many diseases, he again and again used ME/CFS to demonstrate its worth.

Ron Davis asked how a major disease could get so little attention

He started out by noting that chronic fatigue syndrome (ME/CFS) is more common than HIV, Parkinson's and multiple sclerosis, and too wondered how such a common disease could be so unknown. It's the lowest funded of any major disease. ME/CFS receives just 0.1% of the money that goes to HIV research.

Davis was on a roll, joking and delivering pointed comments to the audience. He said his job description was "reducing noise"; i.e. finding ways to deliver vast amounts of meaningful clean data, cheaply and efficiently. Davis presented a cornucopia of new technologies his lab was working.

First up was the nanoneedle. With its 2,500 electrodes per cm measuring whatever they are measuring 200 times a second, the nanoneedle is capable of providing a billion data points in one sample. There was the test able to detect antibodies with 10,000 times more sensitivity than standard Elisa tests and the wearable biosensors that electrically analyze very small amounts of sweat, and eventually cytokines and other immune factors. (They could determine what's happening to people with ME/CFS as they descend into PEM). There was the miniaturized energy harvesting device which uses movement in the blood to generate energy and monitor what's going on there. (It's so small you can't see it.) The way to levitate cells and so on.

It was mind-boggling stuff and then it was onto ME/CFS and Davis's grand fishing expedition.

The Grand Fishing Expedition

Davis said that when you don't have a clear pathophysiological pathway, you look everywhere. We have two grand fishing expeditions underway in ME/CFS; Davis's Open Medicine Foundation study and Avindra Nath's intramural study at the NIH. Medicine research is now so complex that the two hardly overlap. Davis is focusing on getting molecular observations and Nath is including things like metabolic chambers, growing neurons in a dish, autonomic nervous system testing and exercise.

Davis noted that most of the "fishing holes" will not pan out, but in a process of addition by subtraction, the negative results allow you to move past dead ends and onto new possibilities. The key is that you don't step over something by pretending to know more than you know.

The Severe Patient Big Data Study contains 20 ME/CFS patients – so sick they never leave their house – and their families. Because the disease is so prominent in them, Davis believes they may provide a clearer signal. Davis listed 30 tests and gave some early results.

Thus far Davis has found more evidence of viral activity in the healthy controls.

Viruses – In a major surprise, Davis has thus far found no evidence of viral activity in the severely ill. In fact, Davis is finding less viral activity in the severely ill patients than in the healthy controls. The severely ill patients are so clean that Davis is searching for a reason why. He believes their immune systems may be so activated that they're able to immediately repel pathogens. His search for viruses is not done yet but – he'll go after RNA

viruses next – but thus far, there's been no cheese down the viral tunnel!

Toxins – Heavy metal contamination can wreak havoc with many body systems, but no evidence of heavy metal contamination has emerged.

High Omega-3 Levels – Omega 3 is the good omega oil but omega-6 (at the right level) provides important functions as well. In general, the ratio of the severely ill patients' omega-3 to omega-6 levels is out of balance. Davis chalked up the too high omega-3 levels to supplementation and an excellent diet :).

Cell Lysis – too many cells dying and dumping their DNA into the blood can cause problems – but not in ME/CFS.

Mitochondria Levels – energy production in ME/CFS patients could be impaired by low levels of mitochondria but the numbers of mitochondria are fine.

Inflammation – evidence of inflammation is present, but Davis warned that we don't know what is triggering that inflammation and what positive effects it might be having. He noted that the immune activation could be present without a trigger.

Energy Production – Dramatic differences are continuing to show up in metabolic testing (metabolomics). With one third of metabolites greater than two standard deviations below normal, metabolomics is providing the best window into ME/CFS yet. The severely ill patients are showing significantly more metabolomic abnormalities than the moderately ill ME/CFS patients. That suggests that Davis's idea that the severely ill provide a clearer picture of this disease could be true.

Genes – The genomic studies have identified a gene new to ME/CFS research which has been found, if I remember correctly, in every severely ill patient. Expressed mainly in the brain, the gene has been connected to autism – an interesting connection given Bob Naviaux's findings of similar metabolomic results in the two diseases. Davis suspects that ME/CFS is primarily a metabolic disease and is not centered in the brain. That would be good news given the difficulty of studying the brain and accessing it via treatments.

In general, Davis believes the genetic predisposition to ME/CFS is different; instead of featuring a couple of rare polymorphisms, it appears to be manifesting as increased levels of a series of common polymorphisms. Showing that, he said, requires a different kind of approach from what most geneticists do.

Biomarker

Finding a biomarker, Davis said, is essential for proving to the world that ME/CFS is not all in one's head. He holds out the most promise for the nanoneedle and its billion data points. Thus far, the stats are impressive. The nanoneedle has found dramatic declines in the energy production of all 17 ME/CFS patients but none of the healthy controls when faced with a stressor. The relatively small sample size becomes less significant in the face of a statistical finding like that. (The possibility that that result could be caused by chance is $5\times10(-7)$ (or, if I can get my zero's correct $p<.0000007$).) You hardly ever see probability factors that strong in biology.

The nanoneedle has clearly uncovered something dramatically different happening in ME/CFS patients. It'll be exciting to see how the nanoneedle tests out in other diseases and to learn more about exactly what it is uncovering. As it is now, its potential seems immense. After all the bad luck with ME/CFS the nano-needle is a case of serendipity striking. It basically fell into our laps – Davis's lab began working on it before he got heavily involved in ME/CFS, and here it is playing a major role in Davis's search for the cause of ME/CFS.

The OMF's blood flow study is another case of serendipity striking. It came about when SJSU researchers heard about Davis's work and approached him. Davis said the results were too preliminary to talk about that, but thus far, ME/CFS patients' red blood cells were showing reduced deformability and slowed movement. Davis wants a smaller capillary tube to mimic the blood flow through the smaller capillaries, so his lab is doing what it does and creating one.

During the question period, Davis acknowledged that the sedentariness the severely ill ME/CFS experience is likely having massive physiological effects. In truth there's no way to tell how much effect it's having. You can find sedentary healthy controls to match up with sedentary but still somewhat active ME/CFS patients, but it's impossible to find healthy controls who've laid in bed for a year. The closest match are astronauts who laid in bed for a month to mimic the effects of space flight, but Davis's attempt to access NASA's blood samples failed. (The samples had been lost).

Since the conference, the Open Medicine Foundation has

opened a new ME/CFS Center at Harvard, led by long time Davis collaborator, Ron Tompkins. Tompkins, who has participated in numerous studies on sepsis and burns, will be extensively analyzing muscle biopsies of ME/CFS patients. Almost all the studies of ME/CFS have analyzed the blood, but Davis felt that direct analysis of muscle cells could be critically important. A blog on that is upcoming.

Conclusion

If we could just get them to take it on the road…

The talks were received with real interest. In fact, I had got the feeling that they were amongst the two most interesting talks in the conference. Both speakers were treated to a bunch of questions. Dr. Bateman waved off my surprise at the reception they got stating the researchers are always interested when they hear about ME/CFS, it's the doctors she had trouble with. The conference organizer stopped by to remark about how fascinating the talks were. She seemed genuine.

Thinking about it I could see why. It's probably not often that researchers are treated to a fascinating field they probably know nothing about – one goal of the conference – and in such an enticing way. Nobody is better than Dr. Bateman at explicating the clinical side of this illness in a clear and vivid way and Ron Davis was at his best – cajoling, joking with, and even gently taunting his audience. These guys are pros. My one thought as I left the talk was how we could get this duo to take their talk on the road…

To read Cort's report, please go to:

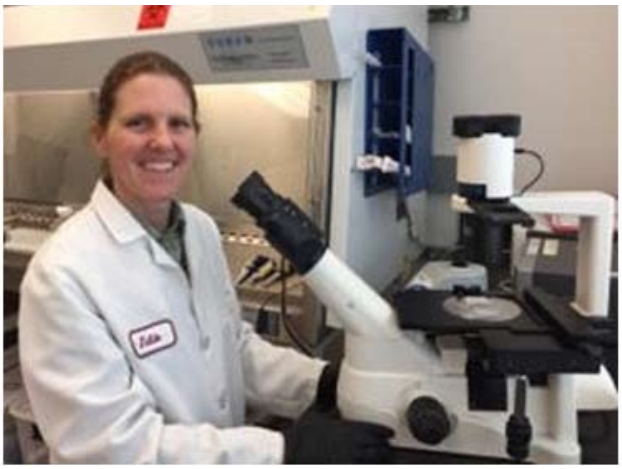
https://www.omf.ngo/2018/06/19/healthrising-dyamic-duo/

[First posted on HealthRising. Reprinted with permission]

Open Medicine Foundation

Meet Julie Wilhelmy, ME/CFS Collaborative Research Center at Stanford Team Member – July 25, 2018

We want to introduce you to one of the extremely talented, dedicated researchers whose work OMF funds thanks to your generous support. We invited ME/CFS Collaborative Research Center at Stanford team member Julie Wilhelmy to share her background and role at the Stanford Genome Technology Center (SGTC). Julie wrote:



Julie Wilhelmy, SGTC

In Julie's words: "As a recent graduate of Washington University in St. Louis, I started working at Stanford in 1999 with Ron Davis sequencing DNA for the Human Genome Project. After its completion in 2003, I joined the Inflammation and Host Response to Injury Program (*http://www.gluegrant.org*) studying the effects of severe systemic inflammation on trauma patients by examining the gene expression levels of various immune cell types at several time points post-injury.

Through a collaboration with Mark Davis, our group decided to focus on Human Leukocyte Antigen (HLA) profiling. As this region of the genome is highly variable and the products of these genes are a major factor in the human response to infection and in autoimmunity, it became evident that obtaining this information from patients with immune-related diseases would be very valuable so we developed a high throughput method to determine the sequence of these genes in many individuals (*http://www.pnas.org/content/109/22/8676*). In 2012, I left Stanford to work in industry, helping to launch a company, Cellular Research Inc., specializing in

counting molecules for gene expression studies.

In 2016, I returned to Stanford to work on the SIPS study for ME/CFS, generating data to analyze the gene expression patterns of the severely ill patients. I also joined Mark Davis's lab in immunology to set up a high throughput pipeline for the analysis of T Cell receptors and gene expression of single cells in his lab to research a number of different diseases. Due to the emergence of increasing amounts of evidence supporting the link between ME/CFS and immunology, we have decided to use this pipeline to examine the T Cell repertoires of our ME/CFS patients as well. In addition, we plan to gather and incorporate HLA sequencing of these same patients for a very comprehensive look at the immune response in ME/CFS.

I am involved in several other projects within our ME/CFS group including the Metabolic Trap Project with Robert Phair, the red blood cell work with Mohsen Nemat-Gorgani and Amit Saha. I work with Layla Cervantes to explore the energy metabolism of ME/CFS patient immune cells using the Seahorse instrument. We both also help support the Nanoneedle platform development with Rahim Esfandyarpour and Alex Kashi by providing patient and healthy cells for standard runs on the instrument as well experiments to further clarify our findings of increased impedance after salt stress in ME/CFS cells.

I'd like to take this opportunity to thank all of the patients who have provided blood samples to our lab so that we can look at the differences between patients and healthy controls with our methods. Some have even donated several times so that we can develop our tools to explore the mechanisms behind ME/CFS. This has been an invaluable resource which has allowed us to progress at a faster pace and we really appreciate the support we have been given by the patient community.

I have never had a chance to work in such proximity to the people affected by the disease I am studying and it has been an eye-opening experience that I will never forget along with the many friendships I have made over the last 2 years. Thanks again!"

[Open Medicine Foundation funds the research of Julie Wilhelmy with her role at Stanford Genome Technology Center.]

AND As the Race Continues

Open Medicine Foundation (OMF) funded Severely ill Big Data Study

This study, led by Drs. Davis and Xiao, included over 1,000 tests per patient, producing, to our knowledge, the biggest dataset ever generated in a cohort of ME/CFS patients. This big data study examined the patients' genome, gene expression, metabolomics, microbiome, cell-free DNA sequencing and quantitation, and cytokines, as well as a range of tests typically performed by clinicians. In 2017, the focus of the study was on analysis, data integration, and making the dataset available to researchers at The Stanford End ME/CFS Data Center (registration required).

OMF Update on Study:

• **Differences** in metabolites, microbiomes, cytokines, and several clinical test results were observed between patients and controls.

• **No significant differences were found for any major DNA viruses** between patients and controls using cell-free DNA from the blood. By using cell-free DNA it was possible to look for even the viruses that can hide behind the blood-brain barrier escaping detection by normal means. In addition, the blood of patients was examined for new pathogens by isolating particles from the blood and using DNA sequencing. No new pathogens were found.

• **SF-36 scores are worse in ME/CFS than in several other major diseases** and correlate the least with depression and mental illnesses. (SF-36 is a questionnaire in which patients report on their fatigue and other aspects of their quality of life.)

• **Genetics** have been a particularly interesting aspect of this study, **as the team has identified several candidate genes that may predispose individuals to develop ME/CFS (or severe ME/CFS)**. This is exciting because it may tell us about the root cause of the disease – which still remains a mystery.

• **Amping up the analysis is a priority** given the complexity of this dataset. OMF has funded a full-time bioinformatician at the Stanford Genome Technology Center to help complete the analysis of this dataset and publish it in the scientific literature, and to continue integrating it with future projects.

Stanford ME/CFS Data Management and Coordination Center

https://www.omf.ngo/2018/05/23/sw-harvard-collaborative-research-center/

Robert Phair, PhD, running the OMF-funded metabolic trap project

Dr. Phair has been collaborating with Dr. Ron Davis for nearly 2 years on investigating mechanisms behind ME/CFS. A project will test a new hypothesis that c ould help explain some of the genetic and metabolic characteristics of ME/CFS patients.

https://www.omf.ngo/2018/03/14/omf-funded-research-a-metabolic-trap-hypothesis-for-me-cfs/

LiveScience - NEWS

Scientists Built a New Microscope to Watch Cells, and the Footage Is Breathtaking

By Brandon Specktor, Senior Writer | April 20, 2018 02:31pm ET

Eric Betzig, a Nobel Prize-winning physicist and group leader at the Howard Hughes Medical Institute's Janella Research Campus in Virginia was concerned that we are not seeing cells in their native state. He and his team decided to do something about that and their quest led to the most candid natural footage of living cells ever taken.

For their new study, the researchers built a custom microscope that is like "three microscopes in one".

To read Mr. Spector's article, please go to:

https://www.livescience.com/62371-living-cell-adaptive-optics-microscopy.html

Harvard video

The Harvard Gazette

https://news.harvard.edu/gazette/story/2018/04/microscopes-3-d-movies-of-cells-open-new-frontier-for-researchers/

SAGE journals

Health Psychology Open

By: Mark Vink, Alexandra Vink-Niese

Multidisciplinary rehabilitation treatment is not effective for myalgic encephalomyelitis/chronic fatigue syndrome: A review of the FatiGo trial

First Published August 6, 2018

Abstract

SAGE journals [Sj] points out that The FatiGo trial's findings that multidisciplinary rehabilitation treatment is more effective for chronic fatigue syndrome/myalgic encephalomyelitis [cfs/me] in the long term than cognitive behaviour therapy [cbt] and more cost effective and better quality of life. However, FatiGo ignored the results of the activity metre and its analysis indicates no statistically significant difference between multidisciplinary rehab and cbt nor are they cost-effective.

http://journals.sagepub.com/doi/full/10.1177/2055102918792648.

Information of Interest

A necessary addition for ME information

Global Advocates 4 Myalgic Encephalomyelitis

https://artzstudios1.wixsite.com/globaladvocatesmeicc

Drug Interaction Checker

You can check for drug interactions when you are prescribed a new medication with which your pharmacist can assist. To view, please go to:

https://www.webmd.com/interaction-checker/default.htm

Customizable To Do List You Can Edit, Print for FREE

https://www.thecreativityexchange.com/2014/11/printable-editable-list.html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FM Overview $7		
TEACH-ME (Eng) $25		
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CPP Disability Guide $10		
Primer-Bilingual Edition $25		
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THE NATIONAL ME/FM ACTION NETWORK RESOURCES

Quest Newsletter—Free with annual membership of $30.00

When you become a member of the National ME/FM Action Network, you receive our quarterly newsletter QUEST. We keep you informed about medical research, disability and legal issues and on developments affecting the ME/FM community in Canada and internationally.

ME/CFS and FM Brochures - FREE

Coloured pamphlets on ME/CFS and FM are available in English and French. You can view them on our website

Consensus Documents for ME/CFS and FM

- Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols [Journal of Chronic Fatigue Syndrome, Vol. 11, No. 1, 2003. Haworth Press 2003/2004 ISBN:0-7890-2207 9]
- The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners [Haworth Press, 2004 (Soft cover book) ISBN 0-7890-2574-4]

The consensus documents are available at Amazon.ca or at Chapters.ca or view them on our website.

ME/CFS and FM Overviews - $7.00

The ME/CFS and FM Overviews are summaries of the Canadian Consensus documents.

- You can view the ME/CFS Overview in English, French, Spanish, German, Italian and Dutch on our website. English versions of the ME/CFS Overviews are available for purchase from the National ME/FM Action Network. French versions of the ME/CFS Overview are available for purchase from Quebce Association for ME, AQEM (aqem.ca)- call (514) 369-0386 or 1-855-369-0386 or email info@aqem.ca.
- You can view the FM Overview in English, French, Spanish and Italian on our website. English versions of the FM Overview are available for purchase from the National ME/FM Action Network.

TEACH-ME (Second Edition) - $25.00

Our TEACH-ME Source Book is for Parents and Teachers of children and youth with ME/CFS and/or FM. This document is available in English and French.

CANADA PENSION PLAN DISABILITY GUIDE 2015 Edition- $10.00

A Guide designed for those who are disabled and wish to apply for Canada Pension Plan Disability Benefits. It outlines the various steps in the process.

Chronic Fatigue Syndrome / Myalgic Encephalomyelitis - Primer for Clinical Practitioners
Syndrome de fatigue chronique Encéphalomyélite myalgique - Petit guide pour la médecine clinique - $25.00

The ME/CFS Primer was produced by the International Association for Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (IACFS/ME). It was translated into French by the National ME/FM Action Network. You can view both the English and the French on our website. Bilingual versions are available for purchase from the National ME/FM Action Network.

All of the above resources can be viewed on the
National ME/FM Action Network website at http://mefmaction.com

NATIONAL ME/FM ACTION NETWORK

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