NATIONAL ME/FM ACTION NETWORK
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COVID-19 Vaccines

We have received a number of inquiries about whether or not people with ME or FM should have COVID vaccines. We would like to share with you bulletins that we have received from the American Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Society (AMMES) and from ME/CFSCommunity.com. Please keep in mind that these are US sources. Two key differences are that the rate of infection is lower in Canada than in the US and the availability of vaccines is different. But we think you will find the information very helpful.

Should People With ME/CFS Get the COVID Vaccine?

from the American Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Society (AMMES)

With the pandemic still in full swing, and a vaccine on its way to the public, many people with ME/CFS are wondering if they should get vaccinated. This is not an idle question, nor is it easy to answer. Many people with ME/CFS have immune system alterations that can make a vaccine dangerous (anaphylaxis) or, conversely, render it ineffectual. (Immuno-suppressed individuals may not develop antibodies.)

Individuals with allergies or who are highly reactive need to proceed with caution. England's National Health Service has issued a warning that people "with a history of a significant allergic reaction to a vaccine, medicine or food" may experience serious allergic reactions (anaphylaxis).

Both the Pfizer-BioNTech COVID-19 and the Moderna vaccine contain messenger RNA (mRNA) of the virus. The mRNA encodes the viral spike glycoprotein of

SARS-CoV-2. The vaccines do not contain viral fragments. Nor do they contain preservatives. In addition to the active ingredient, the vaccines contain salts and sucrose. To protect the mRNA, the vaccines also include lipids.

Of those lipids, polyethylene glycol may prove to be problematic to individuals sensitive to petrochemicals. (Polyethylene glycol is the main ingredient in anti-freeze.) The amount of polyethylene glycol in the vaccine is tiny, but people with chemical sensitivities can react to miniscule amounts of any chemical.

In sum, the jury is still out on whether people with ME/CFS should take the vaccine. Pregnant and lactating women, as well as children under the age of 12 have not been recommended to take the vaccine, which shows that while it is generally considered safe, for some populations there are risks.

However, it is equally important to bear in mind that Covid-19 can be fatal. Even in our vulnerable patient population, the risks need to be balanced against the possibility that we may lose our lives if infected with the virus.

Dr. Bateman, from the Bateman Horne Center recommends the following:

"*We [the world] certainly need COVID-19 vaccines desperately and everyone who is healthy enough for the vaccine should get vaccinated, starting with those at highest risk of COVID exposure. This includes healthy family members of vulnerable people. For the ME/CFS/FM population, my advice is to stay safely quarantined and wait a couple of months while the vaccine is distributed and broadly administered. Because of the large numbers and close monitoring, we should know fairly quickly how people do with the vaccines. This advice will apply as each new branded vaccine is approved and rolled out. In general, the people who should be most cautious are those who have previously had allergic reactions to vaccines or are prone to severe allergic reactions in general. If you decide to get the vaccine, be rested and stable prior to the vaccine, and plan on resting/relaxing for at least 72 hours afterward. Supportive care will include anything you usually do for flu symptoms, PEM, allergy flares, worsened orthostatic intolerance, etc. If anything, including a vaccine, makes you sick enough that you are unable to maintain adequate fluids and nutrition, or results in fluid and electrolyte losses (sweating, diarrhea, etc), it is always appropriate to seek IV fluids as a primary intervention.*"

Should I take the COVID-19 vaccine when it becomes available?

Answered by Dr Charles Lapp MD

Many PWCs (Persons with CFS or FM) have developed a flare or relapse after vaccination with live viruses, so we have always recommended avoiding immunization with influenza vaccine, the MMR, and Hepatitis B, if feasible. The question is: how safe are the COVID-19 vaccines?

Currently there are at least 52 COVID vaccines in clinical trials according to the WHO, two of which will be imminently available in the USA. These are produced by Pfizer and Moderna here in America. Products by Astra-Zeneca and Johnson & Johnson are not far behind.

The Pfizer and Moderna products are not made from live virus, so they are not likely to cause flares or relapses in our PWCs. They both require two doses 21 to 28 days apart. It takes about 2-3 weeks to develop a 50% level of immunity after the first dose, and that level persists for just a few weeks so the second immunization is necessary. The vaccines are about 90-95% effective, but there is no data yet on how long such immunity will last. Side effects of the vaccination include injection site soreness and fever in most cases, increased fatigue (up to 60%), headache (up to 50%), muscle aches (37%), and chills (32%), especially after the second jab. These symptoms resolve in 24 to 48 hours, and a minority of individuals has to take Tylenol or other remedies for them.

Our concern is not the short term effects, but long term. The Pfizer and Moderna vaccines have been administered safely to thousands of individuals already, but new issues are likely to arise after millions of individuals have been immunized. Time will tell. This is currently a moot point since the vaccines will be provided first to medical

providers, health care workers, nursing home residents, prison inmates, and first responders. It will probably be many months before they will be available to the public, so we will probably have a much better idea about long term effects by then.

Because COVID-19 is such a severe disease we currently recommend that high risk individuals strongly consider vaccination. These include individuals with high blood pressure, diabetes, obesity, asthma or pulmonary disease, cardiovascular disease, and immune deficiency. The vaccines have not been adequately tested in pregnant or lactating women, or in children under 16 years.

Since PWCs frequently suffer immune dysregulation, many wonder if they should be considered "immune deficient." Our opinion is that many patients have an UP-regulated immune system and fend off viruses readily, so they rarely fall ill. If you are the type of individual who "catches every virus that comes along," then you are probably in the minority of DOWN-regulated patients and should highly consider the vaccination when it is available.

Despite immunization there is still a small but significant chance one could contract COVID-19; therefore, prevention is KEY. Dr. Lapp has just reviewed dozens of past epidemics and one point is clear: frequent washing, hand sanitizing, face masks, and isolation are crucial for avoiding infection.

To vaccinate or not - with ME/CFS

by Dr Nancy Klimas

I have been asked this question dozens of times over the past week. This is my opinion –

COVID kills people. It kills people with over activated and damaged immune systems preferentially – and that is what ME/CFS is all about. So while there certainly is a risk of an ME relapse with these hyper reactive vaccines (the first wave to be released), you have to weigh the possibility of an ME relapse against the risk of death from COVID.

You can mitigate the risk in a number of ways - just the way you do when you feel a relapse coming on. Before the vaccine make sure you are taking enough antioxidants, particularly NAC or glutathione and coQ10. The big mediator of post vaccination relapse and immediate reactions is mast cell activation. If it happens

immediately, that is anaphylaxis, but if it happens slowly and low grade over days the mediators mast cells release can drive a classic ME/CFS relapse. So, take an antihistamine before and for several days after the vaccine – the strongest one you tolerate. (Benadryl is one of the strongest, Zyrtec is another good choice). There are many mast cell stabilizers, watch Dr. Maitlands excellent lecture on our web page from the recent conference we sponsored on the subject if you want to know more: **Managing the Syndrome Soup: POTS, EDS, MCAS & ME/CFS** *https://www.nova.edu/nim/events.html*

There are natural supplements that act to block or clear histamine and stabilize mast cells such as alpha lipoic acid, ascorbic acid, B6, diamine oxidase enzymes (DAO), luteolin, N-acetylcysteine (NAC), Omega-3's, riboflavin, SAMe, quercetin, and natural sources of theophylline like green and black teas. If you have been diagnosed with mast cell activation syndrome it would make sense that your risk of an immediate reaction to any vaccine should be higher, though the data on the risk to people with mast cell activation syndrome or prior vaccine allergic reactions is not yet known with the COVID vaccines. I suspect we will know fairly quickly, with millions of doses already administered. So you may want to wait (taking all of the COVID precautions very seriously) and when you do take the vaccine plan to stay in the medical setting for at least 30 minutes, consider several hours, to be in a safe place if you do have a reaction. In this special circumstance premedication with a steroid, the same way we premedicate people who need a CT scan with iodine contrast dye, could be provided by your physician.

Please note that if you take the vaccine you should take the whole dose, and the current vaccines, Pfizer and Moderna, should be administered twice. It is not yet known how long the immunity will last, but there are blood tests that look at antibody levels available. They came to market very quickly, we will know more about the quality of the antibody tests over the next few months. Most importantly, vaccination is not 100% (in fact the two initial vaccines trials were 95% effective in preventing or reducing the severity of infection) So vaccination does not exclude strict distancing guidelines, and the masks continue until "herd immunity" levels of vaccination have been reached (70% of the population)!

Of course, these recommendations are simply my opinion, and we will know a lot more about safety in the coming months – but 30,000 plus folks took the vaccines in the trials (that's a lot) and you have to be moved by the photos of health care professionals lining up to receive their vaccine. Is there a risk? Yes. Certainly more a risk of ME/CFS relapse than anaphylaxis, which should be manageable. Is it worth it? Your decision, weighing all that you can find out. But more than 330,000 Americans have died and the new strain of the virus is likely to make our current rate of infection go much higher. Please take this seriously.

More than you wanted to know:

Partial vs. absolute protection

Most vaccines offer incomplete protection against infection and this is likely to be the case with SARS-CoV-2 vaccines as well. However, even partial protection will be of benefit both to patients and the general public. Partial protection may mean that most but not all persons develop immunity, or that some recipients develop weak immunity that makes the consequences of infection less severe than they would have been otherwise.

(December 2020 update: Information from the American College of Rheumatology Regarding Vaccination Against SARS-CoV-2).

Here are the official recommendations:

The American College of Allergy, Asthma, and Immunology (ACAAI) has issued guidance for physicians and other providers related to the risk of an allergic reaction following vaccination with an mRNA-based coronavirus disease 2019 (COVID-19) vaccine.

ACAAI's recommendations are in line with guidance issued by the Centers for Disease Control and Prevention. Specifically, that patients experiencing a severe allergic reaction after getting the first shot should not receive the second shot.

In addition, the ACAAI COVID-19 Vaccine Task Force recommends the following guidance for physicians and other providers:

- The mRNA COVID-19 vaccines should be administered in a healthcare setting where anaphylaxis can be treated. All individuals must be observed for at least 15 to 30 minutes after injection to monitor for any adverse reaction. All anaphylactic reactions should be managed immediately with epinephrine as first-line treatment.
- The mRNA COVID-19 vaccines should not be administered to individuals with a known history of a severe allergic reaction to any component of the vaccine. Although the specific vaccine component causing the anaphylaxis has not been identified, polyethylene glycol is one of its ingredients and has been known to cause anaphylaxis.
- Data related to risk in individuals with a history of allergic reactions to previous vaccinations and/or mast cell activation syndrome/idiopathic anaphylaxis is very limited and evolving. A decision to receive either of the mRNA COVID-19 vaccines that are currently approved for Emergency Use Authorisation by the US Food and Drug Administration should be undertaken by the individual, along with their physician or other provider administering the vaccine using their professional judgment balancing the benefits and risks associated with taking the vaccine.
- People with common allergies to medications, foods, inhalants, insects and latex are no more likely than the general public to have an allergic reaction to the mRNA COVID-19 vaccines. Those patients should be informed of the benefits of the vaccine versus its risks.
- The mRNA COVID-19 vaccines are not live vaccines and can be administered to immunocompromised patients. Physicians and other providers should inform such immunocompromised patients of the possibility of a diminished immune response to the vaccines.

Reference: *https://acaai.org/news/acaai-provides-further-guidance-risk-allergic-reactions-mrna-covid-19-vaccines*

SOURCE: American College of Allergy, Asthma, and Immunology

The American College of Rheumatology offers additional guidance for people on immunosuppressive therapy, and discussed in some detail the issues around vaccination and herd immunity. Here is the link:

https://www.rheumatology.org/Portals/0/Files/ACR-Information-Vaccination-Against-SARS-CoV-2.pdf

Still, I think 2021 will be a happy new year. The most vulnerable should see the vaccines available in the coming weeks! And yes, it will take a lot to get our citizens to the level of herd immunity with mostly the logistics in the news, but really it is denial of the risk of COVID 19 allowing this head in the sand thinking. Take a hard look at the stats and your risk. Then make a smart decision.

Nancy

There is additional information and discussion about vaccines at

https://www.healthrising.org/blog/2021/01/03/chronic-fatigue-fibromyalgia-experts-coronavirus-vaccine/

Prestige of Diseases and Disabilities

Introduction

Around the time that the last issue of Quest was finalized, two very interesting studies were published.

The first is a statistical study that found that the US National Institutes of Health is more likely to under-fund female diseases than male diseases. Also interesting were the exceptions to the rule – a male dominant disease was under-funded and some female dominant diseases that were over-funded. This led the author to raise the issue of disease stigma. For the record, ME was the most under-funded disease in the study and FM was not included.

The second is a review of the outbreak of ME at Royal Free Hospital in 1955 and the aftermath. Fifteen years after the outbreak, two psychiatrists published a report attributing the outbreak to mass hysteria. This has stigmatized ME to this day. The new article refutes the arguments that the psychiatrists used to justify the mass hysteria explanation and asks how this stigmatizing theory was allowed to take hold.

These two studies brought to mind two studies from Norway several years ago which dealt with disease and disability prestige. High prestige means a disease or disability is respected. Low prestige is another way of saying that the disease or disability is stigmatized. Prestige, along with money and power, are seen as valuable resources.

One of the Norwegian studies reviewed the results of a survey that was conducted in 1990, 2002 and 2014. Each time, physicians were asked to rate 38 disease categories according to the prestige they believed health personnel would in general award the disease. The results were compiled and the diseases were ranked. The study found that rankings changed very little. For instance, Fibromyalgia ranked last in all three surveys. ME was not included. There was one disease category that did rise up the rankings over the years and the authors explore why.

The other Norwegian study asked professionals at disability organizations to rate 38 chronic disease/disability categories (a slightly different list). These results were compiled and the authors tried to explain the rankings. ME ranked 33rd and FM ranked 37th.

Low prestige is a fact of life for ME and FM. The purpose of looking at these studies is not to feel sorry for ME and FM. It is to explore why ME and FM are not considered prestigious and to consider how their prestige can be raised.

Gender (and prestige) disparities in NIH research funding

In Quest 110, we discussed a 2016 study that showed that ME was receiving far less than it would if NIH research funding were based on burden of illness. This study built on a study done by NIH which calculated burden of illness figures for a number of health conditions (not including ME/CFS, FM or MCS) and matched the burden of illness figures with NIH funding figures.

The 2016 study calculated a burden of illness figure for ME/CFS and added it to the mix. The information was graphed. The horizontal axis was disease burden and the

vertical axis was NIH funding for the disease. Then a regression line was drawn to represent fair funding based on disease burden. For any point on the line, the disease was receiving what it would if disease burden was the exclusive criteria. For any point above the line, the disease was over-funded. For any point below the line, the disease was under-funded.

The latest study updated the NIH funding and burden of illness figures and recalculated the line. Then it calculated funding ratios by dividing what the disease was actually receiving by what the disease would be receiving if funding were based on burden of illness. Diseases on the line are receiving fair funding and have a ratio of one. Disease above the line are over-funded and have a ratio greater than one. Diseases below the line are under-funded and have a ratio less than one. For example, for 2019, HIV/AIDS had a ratio of 17.7953 which means it was receiving over 17 times what it should. ME/CFS had a ratio of 0.0610 which means it was receiving only about 6% of what it should. HIV/AIDS was the most over-funded and ME/CFS was the most under-funded disease in the study.

Then the author looked at the gender profile of each disease. He found that "in nearly three-quarters of the cases where a disease afflicts primarily one gender, the funding pattern favours males, in that either the disease affects more women and is underfunded (with respect to burden), or the disease affects more men and is overfunded."

Looking at the list of over and underfunded diseases, one finds a male dominant disease that is underfunded (liver cancer) and some female dominant diseases that are overfunded (such as breast cancer). Gender is not the only factor influencing decisions. Disease prestige plays a part as well.

But how do gender and prestige disparities enter into the decision making process? NIH has pointed out that, in addition to disease burden, its funding decision consider scientific merit, scientific opportunity, portfolio balance and budgetary considerations. There seem to be two routes to introduce disparities. Scientific merit suggests funding of well-respected topics and scientific opportunity suggests continuing to fund work that is already underway.

It would be extremely difficult to reproduce this study in full in Canada because of data gaps. The work we have been able to do strongly suggests that similar results would be found in Canada. The legislation governing CIHR asks them to work toward "improved health for Canadians, more effective health services and products and a strengthened Canadian health care system". They are asked to do this "according to international standards of scientific excellence", and this provides an opening to introduce disparities into Canadian research. The situation could be very different if they were explicitly asked to achieve these goals "according to Canadian values of equity and inclusion".

The study is found at: *https://www.researchgate.net/publication/346624084_Gender_Disparity_in_the_Funding_of_Diseases_by_the_US_National_Institutes_of_Health*

Looking back at the Royal Free Hospital experience

In 1955, there was a disease outbreak among staff at the Royal Free Hospital and in the surrounding community. Some of the people affected went on to develop long term symptoms. A 1956 article described the symptoms, tied in several other previous outbreaks, and suggested the name Myalgic Encephalomyelitis.

Fifteen years after the outbreak, two psychiatrists reviewed case files and attributed the Royal Free outbreak and other outbreaks to mass hysteria, seeding doubt about the reality of ME.

Rosemary Underhill was a medical student at the Royal Free Hospital in 1955. Because she was a student, she was excluded from the hospital so was not involved in patient care. Around 2013, 58 years after the outbreak, Dr Underhill and a fellow student from that time tracked down people who were at the hospital during the outbreak and explored the underpinnings of the mass hysteria idea. Their findings were published in the journal Medicina in

December 2020. Their article shows the techniques used in the 1970 article to discredit the illness.

The following is a quote from the 1970 article justifying the idea of mass hysteria. It has been reformatted into bullets and several explanations have been inserted:

...it is concluded that there is little evidence of an organic disease affecting the central nervous system and that epidemic hysteria is a much more likely explanation. The data which supports this hypothesis are:

- *the high attack rate in females compared with males;*
- *the intensity of the malaise compared with the slight pyrexia [fever];*
- *the presence of subjective features similar to those seen in a previous epidemic of hysterical over-breathing;*
- *the glove-and-stocking distribution of the anesthesia [pain in the legs and hands, peripheral neuropathy]; and*
- *the normal findings in special investigations.*

Finally, a deliberate attempt by one of the authors to produce an electromyographic record similar to that reported in Royal Free disease was successful.

The 2020 paper attacks the arguments for mass hysteria point by point. The authors give evidence of organic disease. As for the female to male ratio used in the 1970 article, there were two problems. Firstly, one would expect that more females would be affected because there was more female staff in the first place. Secondly, the "attack rate" use in the 1970 report for females was higher than the rate found by the hospital while the attack rate for males was lower than the rate found by the hospital. Overall, however, the attack rate for females was higher than for males and the number of women who developed ME was higher than the number of males, but that is common in diseases and does not prove hysteria. The 2020 paper points out that fever is not a symptom of hysteria. Several patients had raised respiratory rates which the psychiatrists attributed to over-breathing and then they speculated that other patients were hiding their over-breathing. The 2020 paper notes that peripheral neuropathy can be a symptom of serious disease. It notes that the ability of a healthy person to supposedly reproduce a test result does not prove hysteria. And it notes that hysteria is transmitted quite spontaneously and fades when patients are separated, whereas there was a several day incubation period among the Royal Free patients and the symptoms continued even after discharge when they were not in contact with other patients.

The 2020 article describes some factors which allow the psychosomatic position to be considered:

- *the etiology is uncertain*
- *there is no biomarker*
- *diagnostic criteria are based on clinical symptoms and the exclusion of other fatiguing illnesses*
- *there are no pathognomonic [specific] physical signs*
- *patients do not look ill even when severely affected by the disease*
- *there is no curative medication.*

Obviously, gender was a factor as well even if the authors do not list it specifically.

The study is found at:
https://www.mdpi.com/1010-660X/57/1/12

Disease Prestige

The authors of this study looked at three cycles of a survey of Norwegian physicians and asked this research question: Does the disease prestige hierarchy change over time? The authors found that little had changed over 25 years. Leukemia, brain tumour and myocardial infarction were in the top three in each of the survey cycles. Fibromyalgia was last all three times, with depressive neurosis, hepatocirrhosis and anxiety neurosis joining it in the bottom four. ME wasn't included.

The authors identified three factors in disease prestige.

- *Disease characteristics and disease trajectory: Non-self-inflicted, acute and lethal diseases with clear diagnostic signs, located in the upper part of the body, preferably the brain or the heart, are typically awarded high prestige.*
- *Disease treatment: Disease categories associated with active, risky and high technology treatment leading to a speedy and effective recovery are awarded high prestige.*
- *Typical patients with the disease: Disease categories associated with young patients, patients who accept the physician's understanding of the disease, and whose treatment results do not involve disfigurement, helplessness or other heavy burdens, are awarded high prestige.*

The authors apply this framework to low prestige fibromyalgia. "Diffuse bodily complaints are more problematic in medicine than the 'pure' psychological ailments. Besides, most of the fibromyalgia patients maintain understandings of their condition quite different from that of their doctors. Fibromyalgia is much more common among women than among men. A question is whether this in itself results in low prestige. Those we have interviewed say the other traits are the reason for the low prestige of this disease category." (Later, the authors note that the interrelationship between disease prestige and gender has not been resolved and "is clearly a topic worthy of further research".)

One disease (apoplexy or brain stroke) did rise from 33rd to 29th to 23rd place over that time period. A different researcher tried to explain the first increase. "He argued that advances in research, technology and treatment had turned apoplexy into an acute disease. He further described how the main tasks of stroke units had gone 'from monitoring and mobilization to active medicinal and endovascular interventions'". It isn't that the prestige criteria changed. It is that there were "publicly acknowledged changes regarding the disease and its treatment".

The study is found at *https://www.sciencedirect.com/science/article/abs/pii/S027795361400776X*

Chronic disease / disability prestige

This study also came out of Norway. The researchers asked professionals from Norwegian disability organizations to score 38 chronic diseases or disabilities "based on the prestige you believe it has among professionals in the disability field". The top ranked categories were heart attack and various cancers. Blindness, deafness, autism and Down's syndrome were among the mid-ranked conditions. ME, anxiety, restricted growth, FM and cirrhosis were the bottom five.

(An interesting point to note is that AIDS ranked near the middle in terms of prestige but has the highest rate of NIH funding. Sociological theory talks about three resources - prestige, money and power. AIDS used power to get the attention of NIH, and presumably to maintain it.)

The author's suggested three factors in prestige. "First, that high prestige is accorded the conditions that are most clearly defined in medical terms. Second, that high prestige was also accorded to conditions that are represented by large, rich and prominent NGOs [Non-Governmental Organizations]. And third, that low prestige is accorded to the conditions associated with mental illness or symptoms that cannot readily be localized or, in some cases, verified.

The study is found at *https://pubmed.ncbi.nlm.nih.gov/25461875/*

Discussion

The studies validate what individuals in the ME/FM community already know. ME and FM have low prestige and that is largely a result of patients not appearing ill, lack of biomarkers and lack of quick fixes that make the medical system feel good. Being female dominated illnesses helps perpetuate the stigma. Individuals in the ME/FM community can try to improve their individual prestige in their relationships with the health and disability providers, but major changes need collective action.

The studies validate what ME/FM advocacy organizations already know. ME and FM are caught in a vicious cycle where lack of prestige leads to lack of attention by the research, health and disability systems, and the lack of attention by the research, health and disability system reinforce the lack of prestige.

The studies do provide tools to use in confronting the vicious cycle. The study of NIH funding shows unevenness in research funding. The Royal Free article shows how misinformation was able to take hold. The surveys of Norwegian physicians and disability professionals demonstrate that there are prejudices in the health and disability systems.

Multidisciplinary Team Approach to Care

The US Centers for Disease Control and Prevention (CDC) posts bulletins describing the types of studies that it is interested in funding. In the December amendment to a bulletin on COVID, it announced that it would like to see studies into multi-disciplinary team approaches to "long COVID, ME/CFS and other post-infectious fatiguing illnesses, with the goal of improving the quality of life of those affected and supporting their recovery". The full description is quoted below.

It is not clear what would be included under "other post-infections fatiguing illnesses. Fibromyalgia certainly should be. After all, in his study of post-SARS, Dr Moldofsky found that "[t]he clinical and sleep features of chronic post-SARS form a syndrome of chronic fatigue,

pain, weakness, depression and sleep disturbance, which overlaps with the clinical and sleep features of FMS and chronic fatigue syndrome".

It is also not clear what would be included under "multi-disciplinary teams". Would it be a combination of medical specialists (e.g. cardiologists, neurologists, immunologists, pain experts, etc) or a combination of allied health professionals (dieticians, occupational therapists, social workers, etc)? Hopefully, there would be a combination of both groups.

This announcement potentially opens the door to some very important discussions around how ME and FM are addressed in the health system. This announcement also could open the door to ME and FM moving up the prestige hierarchy in the same way that apoplexy (stroke) did in Norway two or three decades ago. The CDC is moving ME and FM from conditions that have been largely ignored to conditions deserving of new, serious consideration by the health system.

We will watch to see how this develops.

Topic # 12: Evaluating and Improving the Clinical Care of Individuals with Chronic Sequelae of SARS-CoV-2 and Other Infections.

12.1: Conduct implementation research to design and evaluate multi-disciplinary team approaches most effective in caring for long COVID, ME/CFS and other post-infectious fatiguing illnesses, with the goal of improving the quality of life of those affected and supporting their recovery.

The SARS CoV-2 pandemic has highlighted the poorly understood clinical syndromes, referred to as post-infectious fatiguing syndromes, that result in significant functional impairment associated with debilitating fatigue, post-exertional malaise, dysautonomia, and cognitive difficulties. Some of these patients have evidence of organ damage and others remain ill with persistent symptoms after SARS-CoV-2 infection without obvious organ damage. The latter group, in particular, have symptoms overlapping those of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

Health systems have designed clinics specifically for COVID "long haulers," and more are cropping up as the pandemic progresses. Given numbers of people infected, even if the percentage who have persistent symptoms is small, it is possible that large numbers of patients will experience post-infectious fatiguing syndromes. Best practices for the evaluation and management of patients with this emerging condition are unclear, and an increasing demand by health care providers for information and treatment interventions is anticipated. Similarities with ME/CFS and post-infectious fatigue suggest that health care providers and patients will experience challenges in communication about the illness and in improving quality of life. The SARS-CoV-2 pandemic presents both an opportunity to apply knowledge gained from more than 30 years of studying ME/CFS, and to gain new insights about post-infectious fatiguing syndromes.

Evidence exists for the effectiveness of multi-disciplinary team approaches to the care of other complex conditions. However, consensus on how teamwork and services are optimally coordinated continues to be a work in progress.

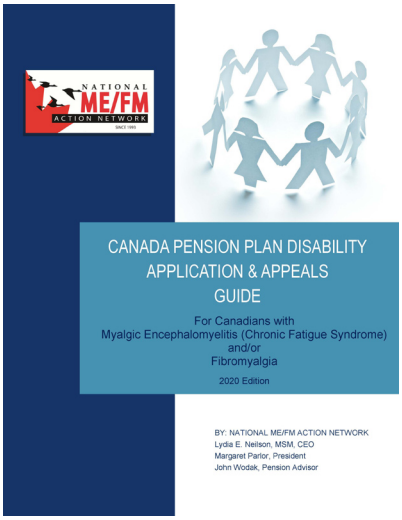
CDC is interested in the development and evaluation of multi-disciplinary team approaches needed to care for patients with chronic sequelae of SARS-CoV-2 (long COVID), ME/CFS and other post-infectious fatiguing illnesses. All solutions should include a mechanism for the open exchange of information broadly among health care providers, including those who are experienced in the care of patients with ME/CFS and other complex post-infectious fatiguing syndromes, in the formative phase of the project and throughout the period of investigation, to facilitate information gathering about design approaches as well as the efficient dissemination of information about evidence-based practices.

The full document is found at *https://govtribe.com/opportunity/federal-contract-opportunity/centers-for-disease-control-fy-21-broad-agency-announcement-75d30121r71738#* Click the pdf at the top of the left column

ME/FM Resources

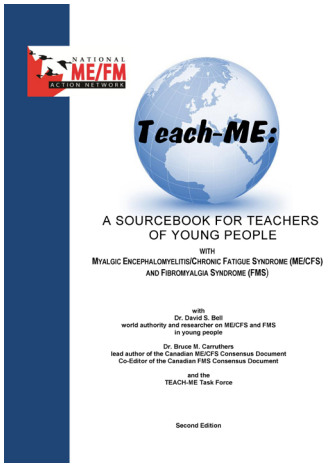
We would like to remind you of some of the resources we have on our website, including:

Canada Pension Application and Appeals Guide



Available in English and French

Teach-ME
A sourcebook for teachers of young people



Available in English and French

Printable Information sheets

ME/CFS in *English and French*

Fibromyalgia in *English and French*

Quest Newsletters

All past issues of our *Quest Newsletters* are available for download on our site.

Medical

Overviews

Review of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: an evidence-based approach to diagnosis and management by clinicians

by Alison C Bested and Lynn M Marshall

Encéphalomyélite myalgique/syndrome de fatigue chronique : une approche basée sur les preuves pour le diagnostic et la gestion dans a médecine clinique

IACFS/ME Primer

ME/CFS PRIMER FOR CLINICAL PRACTITIONERS (2014 REVISION)

You can find as link to the *IACFS/ME Primer* on our website as well as the french translation

Petit guide SFC/EM pour la médecine clinique
– Édition 2014

Federal 2021 Pre-budget Consultations

The federal government invited individuals and organizations to make written submissions regarding the 2021 budget last summer and the Finance Committee heard presentations in the fall. There is still an opportunity to influence the upcoming budget through your Member of Parliament. Some MP's will be holding virtual meetings in the next few weeks and you can simply contact the others. Here are some suggestions of what could be in the budget.

- Pursue the commitment in the Speech from the Throne to a Disability Inclusion Plan which calls for
  - A new Canadian Disability Benefit modelled after the Guaranteed Income Supplement for seniors;
  - A robust employment strategy for Canadians with disabilities;
  - And a better process to determine eligibility for Government disability programs and benefits
- Conduct a study on how the gender and prestige of diseases affect the research funding allocation process.
- Invest in research around the ongoing effects of COVID and study how these effects overlap with existing conditions like Myalgic Encephalomyelitis and Fibromyalgia.

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