

THE NATIONAL FORUM

The National CFIDS Foundation

Vol. 27, No. 1 – Summer 2021

NCF ANNOUNCES NEW GRANT RECIPIENT

By Alan Cocchetto, NCF Medical Director April 22, 2021 – Copyright 2021



The National CFIDS Foundation is pleased to announce their latest research grant recipient, Dr. Jack Wands. Dr. Wands is a Professor of Gastroenterology and Medicine at the Warren Alpert Medical School of Brown University in Providence, Rhode Island. Wands' proposal which is titled, “Aspartate asparaginyl beta-hydroxylase (ASPH) as an etiologic factor in Chronic Fatigue Syndrome (CFS)” has received \$65,000 from the National CFIDS Foundation. Dr. Wands has over 600 peer-reviewed medical journal articles in publication. According to the Foundation, there is evidence that ASPH may be accumulating in the cells of CFS patients. As such, this can dramatically impact the body's response to oxidative stress and hypoxia. Wands has planned both in-vitro as well as in-vivo studies in an attempt to understand the upregulation of ASPH on cell migration and signaling through various cellular pathways following exposure to an oxidative injury. Wands will also be comparing CFS patient samples with those of hepatic cancer patients with cancer-related fatigue.

In addition, Wands has evidence that ASPH overexpression may be a risk factor for the early development of cancer which may be associated with CFS before the disease becomes clinically apparent or in other words, CFS as a pre-malignancy. Wands has observed this in pancreatic cancer patients. This is of importance since the National Cancer Institute has previously reported that CFS has been associated with increases in pancreatic cancer. As a result, Wands and his team have developed innovative animal models and approaches to not only test these concepts, but they have also identified compounds that could be utilized as a potential therapy should these observations pan out. In the last few decades, accumulating evidence has indicated that ASPH expression is upregulated in numerous types of human malignant cancer

and is associated with poor survival and prognosis. ASPH is found on the surface of tumor cells and is highly expressed in cancers of the liver, pancreas, stomach, colon, breast, prostate, lung, and brain. ASPH is associated with tumor cell migration, invasion, motility as well as distant metastatic spread.

According to the National CFIDS Foundation, Chronic Fatigue Syndrome (CFS) is also known as Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) as well as Myalgic Encephalomyelitis (ME). Founded in 1997, the goals of the National CFIDS Foundation are to help fund medical research to find a cause of and to expedite appropriate treatments for the disease. Since its inception, the National CFIDS Foundation has provided \$4.5 million dollars in self-directed research grants to global scientists. The National CFIDS Foundation, an all-volunteer 501(c)(3) federally approved charity, is funded solely by individual contributions. Additional information can be found on the web at www.ncf-net.org or in The National Forum newsletter. The Foundation can be reached at 781-449-3535.

UPDATE: The NCF has reached its goal to raise \$100,000 for Dr. Jack Wands' research. We thank all those patients and families who contributed to this critically important work!

"I believe, as long as the term CFS exists, ME patients will be diagnosed as a minor psychiatric disease by 95% of all physicians."

~ Dr. Byron Hyde

PRESIDENT'S MESSAGE

By Gail Kansky – Copyright 2021

In late February of this year, Japan's Governor Masao Uchibori said at a press briefing about the Fukushima Daiichi Nuclear Plant, "We're still just very near the starting line." The owner of the plant, Tokyo Electric Power Company (TEPCO), thinks it will be roughly 30 more years to remove the fuel debris, dispose of the contaminated cooling water and disassemble the four reactors after the meltdowns and explosions from the earthquake followed by a tsunami less than an hour later. Escaping from the reactors was radioactive steam and hydrogen that accumulated in three of the buildings and exploded. Wall panels and roofs exploded. The contaminated radioactive water has already filled more than 1000 tanks that occupy nearly every available space of the nuclear campus. Japan intends to slowly release this water into the ocean and atmosphere which neighboring nations oppose along with the fishing industry and various

environmental groups. However, Japan will run out of room to store the water by the summer of 2022.

Sand blew into Europe from the Sahara in February and scientists said that sand contained radioactive pollution from tests done in the 1960's! A large area of France was affected, and the sky turned orange just as the snow on the ground did as well! From 1945 through 1980, there were 520 nuclear tests carried out by the United States, France, the Soviet Union, the United Kingdom, and China.

When the National CFIDS Foundation tested its cohort of dozens of CFIDS/ME patients years ago, every single one of them showed up positive for low-dose radiation. In fact, you could tell how much worse some were just by looking at the test results. The worst one, a patient of Dr. Anthony Komaroff, already had cancer. Yes, CFIDS/ME is caused by low-level radiation and slowly works its way toward cancer.

In March of this year, two former prime ministers in Japan urged their country to stop using nuclear power and invest in renewable energy. While they were in office, they were both proponents of nuclear power, but the horrors of the Fukushima Daiichi meltdown had them change their minds.

Our own United States has 94 atomic power stations. One of the nuclear power plants in southern Texas that contributed to the collapse of the grid was due to frozen water pumps. It was not winterized to save money, but all steam turbines should be winterized. Dr. Bernard Lown and his family escaped from Lithuania during the Holocaust with his family when he was a child and grew up in Maine. He co-founded the International Physicians for the Prevention of Nuclear War with his Russian friend, Yevgeny Chazov. That won Dr. Lown and his friend the 1985 Nobel Peace Prize. "Bernie" died this past February at age 99. His work has saved countless lives. The month before he died, however, the Nuclear Regulatory Commission of the United States began to try to extend the operating licenses of their power stations to 100 years. That will mean many more generations of people suffering from CFIDS/ME as well as other illnesses that refuse to expose their cause. After all, our own Department of Defense (DoD) could not find any other charity led by an all-volunteer group that receive no monetary salaries or other compensation. Although no country wants to admit the cause of this worldwide plague called ME/CFS, CFIDS and post-viral fatigue syndrome, there is a lot of scientific proof behind the illness and its low-dose radiation cause that was first announced by the Chernobyl researchers a long time ago. Indeed, over half of their liquidators ended up with ME/CFIDS. Fukushima has merely added to this horror.

PACE UNDER ATTACK

By Kathy Collett (Twitter: @kathycollett7) – Copyright 2021

When it was announced in advance that the draft NICE Guidelines¹ would be deleting the PACE Trial recommendations of GET (graded exercise treatment) and CBT (cognitive behavioral therapy) and later, Cochrane also rejected GET as a treatment option, it was received by ME patients with jubilation and was a turning point. The Guidelines draft stipulated, “Do not offer people with ME any therapy based on physical exercise as a treatment or cure for ME.” Some doctors have referred to the Guidelines and recommended PACE treatments for their patients often without realizing how detrimental graded exercise is and with no understanding of the controversial history. The trial was flawed and unscientific because they moved the goal posts to arrive at the outcome the coauthors wanted. It was conducted 10 years ago and has left a damaging legacy for ME patients. Many who tried it were left bedridden.

In Australia, the leading proponent of graded exercise is Professor Andrew Lloyd at the University of NSW. He set up a clinic for ME patients to undertake GET. He said, “The PACE trial has reasonably solid data.” Yet Dr. Neil MacFarlane, MRC Psych, describes it as “The PACE trial was seriously unethical. The senior researchers continue to deny this, despite the clear evidence. Therefore, the trial is not only at high risk of bias, but of significant risk of fraud and it should be retracted as a trial of treatments.”

The preliminary announcement of the above trial from NICE had the PACE supporters worried. Likewise, the court case involving Dr. Sarah Myhill clearly created concerns for the authors. They felt they were losing their control and so, as in the past, they held an interview praising the treatments. They have relied on media outlets in the UK to present their damaging views. This time it was an interview with the BBC television.

Dr. Clare Garada, the wife of Prof. Sir Simon Wessely², appeared in the BBC interview promoting the treatments as she has done many times before. In an earlier one, she defended PACE even when the journalist questioned the validity of graded exercise. Also appearing to support the PACE trial was Prof. Paul Garner. Then, Prof. M. Sharpe’s Reuters interview promoting PACE and criticizing ME patients by claiming the authors of the published trial had been subjected to abuse lasted one day at #nytimes on Twitter before all signs of it had been removed. They continue to play the victim because the PACE trial recommendations have failed to serve ME as treatments.

Last year, Professor Garner reached out to ME patients on Twitter because he had Covid-19 and, afterwards, felt he had ME. Patients were sympathetic and offered advice and experiences. He could walk 5 km a day as well as dive which is something that alludes ME patients, so he clearly did not have ME. What was also alarming was that he had no qualms about

breaking the lockdown rules during the pandemic and he posted photos of himself in the Caribbean! Before long, he said he had overcome it and he joined forces with Professor Sir Simon Wessely's wife in the media interview. What I find interesting is that academics on Twitter announce that their views are their own, thereby distancing them from the place of employment or university. Prof. Garner clearly does not seem to be concerned that his views reflect on the Liverpool School of Tropical Medicine where he works.

It is believed that Prof. Garner may have a large grant to study Covid-19 and GET. This has shocked ME patients due to his lack of understanding. It reminds me of when Dr. Jay Goldstein commented to a doctor who was receiving research grants for ME and said, "I didn't know you knew anything about ME." The doctor replied, "I don't. I am very good at writing grant applications."

On February 16th, Busse and colleagues composed a response which was published in the BMJ (British Medical Journal). They criticized the NICE committee for removing CBT and GET from the draft guidelines and described it as "a disastrous misapplication of GRADE methodology." NICE has, in fact, provided hundreds of pages with extra documentation and GRADE tables.

A UK psychologist, Oliver James, said, "Cognitive behavioral therapy is a scam and waste of time." He noted that two years later, there was no difference between those who had it and those that did not. Added to the injustices, it has been revealed that ME research and information has been sealed and is not available for release until 2073 in the UK. A blog written by Valerie Eliot Smith in August of 2012 revealed that some secret files were set up hurriedly in order to counteract some misinformation at the time. The files are held at The National Archives (TNA) at Kew in London, UK.

There are two files, one from the Department of Work and Pensions (DWP), formally known as the Department of Social Security (DSS), and one from the Medical Research Council (MRC). These files contain documents about ME (correspondence, notes of meetings, background material, and details of benefit claims/research applications). Because each file contained information which was properly exempt from disclosure under the ACT, they were closed to the public until 2072 (DWP) and 2071 (MRC).

Patients, some of whom were bedridden, have fought to be accepted, so the NICE retraction of GET and CBT is a welcome change. This follows the removal of CBT/GET as treatments for ME patients by the US's CDC. Both have been removed from the CDC's website. The CDC now states that "while vigorous aerobic exercise can be beneficial for many chronic illnesses, patients with ME/CFS do not tolerate such exercise routines."

Professor Brian Hughes and David Tuller published a paper to the Journal of Health Psychology responding to PACE. To read more, see: Trial By Error: Journal of Health Psychology Publishes Hughes-Tuller Critique of Wessely-Chalder CBT Claims

(<https://www.virology.ws/2021/04/10/trial-by-error-journal-of-health-psychology-publishes-hughes-tuller-critique-of-wessely-chalder-cbt-claims/>)

¹ August is the amended release date for the revised NICE guidelines.

² During his interview on Desert Discs BBC Radio, he said, “I don’t want to defend what I do.”

“Neurotransmitters, chemical substances that act as information messengers in the brain are abnormally low in Myalgic Encephalomyelitis. Norepinephrine and dopamine are two such neurotransmitters lacking in PWME.”

~ Dr. Jay A. Goldstein

SHOPPING ONLINE?

Use **iGive.com** or **smile.amazon.com** and a portion of your expense will benefit the National CFIDS Foundation when you list us as your cause!

JUST ASK!

By Alan Cocchetto, NCF Medical Director – Copyright 2021



The “Just Ask” column is intended to act as a means for patients to inquire about issues related to the NCF’s research activities. This column is NOT intended to act as medical advice in any way, shape or form. The National CFIDS Foundation assumes no responsibility for any action or treatment undertaken by readers. For medical advice, please consult your own personal healthcare providers.

Q: My primary care doctor believes that CFS is just, as he says, a “madhouse of infections.” I have shown him some of the NCF’s radiation findings but to no avail. Any comments on this?

A: The NCF frequently gets this question or something similar to this all the time. Most physicians know very little about radiation and its effects on the human body due to how little is taught in medical school on this topic. Furthermore, the concept of low-level environmental radiation exposure, let alone internal radiation exposure, is something very foreign to them. As such, it is much easier for them to understand and accept an infectious disease process since they have all studied microbiology! However, it is noteworthy to make some comments that are certainly applicable here.

Radiation is unique in that if it is internal to the body, then this represents a chronic source of irritation due to chronic radiation exposure. The effects of radiation are based on the type of radionuclide (alpha, gamma etc.), the amount of exposure, duration of exposure and the half-life of the radionuclide. For example, some of our patients have had internal exposure to

uranium. Obviously, this was an environmental exposure and therefore would make CFIDS/ME an environmental disorder. Radionuclides have been found, in significant levels, in drinking water, the food chain, etc. Since uranium has a very long half-life, the patient will be “glowing” for centuries while in the grave. Extremely small levels (picogram to microgram) can be deadly. One has only to look at the death of Alexander Litvinenko, via polonium, to get an idea as to how bad it can be. Now if you dial back the amount, then it could take decades to become a killer. In the meantime, you don’t live a great life because you’re being poisoned. You get my drift.

What’s interesting about radiation is that there are two populations of cells at play. Those that are directly hit by the radiation and those cells that are within the proximity of a cell that takes a direct hit. The last one is called the bystander effect and it is very damaging since about one-third of the cells surrounding a direct hit cell will undergo serious changes.

One of the key ideas regarding radiation is the following. Radiation is capable of affecting all cell types and all tissue types. A virus, bacteria, fungus, parasite etc. cannot do this thereby making radiation unique. Radiation alters the cell membrane, cell metabolism, cell signaling as well as cell functionality. According to the late Dr. John Gofman, of the Lawrence Radiation Laboratory, “No evidence exists that there is a safe tolerance dose of radiation.”

What is needed in the CFIDS/ME community is an awakening to carefully and realistically consider the real “possibility” that CFIDS/ME is related to environmental contamination with radionuclides that have become prevalent in both the food and water supplies. Why is it that Chernobyl scientists found that over 60% of all liquidators/cleanup workers developed Chronic Fatigue Syndrome? The Russians and Ukrainians acknowledged it, why can’t anyone else even consider this possibility? The NCF cannot say what percentage of PWC/ME patients have radiation exposure but some day in the future we will.

“I split my clinical time between the two illnesses (HIV and CFIDS/ME), and I can tell you if I had to choose between the two illnesses, I would rather have HIV.”

~ Dr. Nancy G. Klimas

DR. JAY GOLDSTEIN (1943-2021)

By Alan Cocchetto – Copyright 2021

Dr. Jay A. Goldstein had seen over 20,000 patients at the Chronic Fatigue Syndrome Institutes in Anaheim Hills and Santa Monica, California. Dr. Goldstein had specialized in CFS and related disorders for years and had been interested in the illness since 1985. He had written numerous books on the topic including *Betrayal by the Brain: The Neurologic Basis of CFS, FM and related neural network disorders* (1996), *Chronic Fatigue Syndromes: The Limbic Hypothesis* (1993), and *Chronic Fatigue Syndrome: The Struggle for Health* (1990). He was also the author of *Symptoms and Solutions*. He was a contributing editor to the *CFS Encyclopedia, The Clinical and Scientific Basis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome*, published in 1992.

Dr. Goldstein had been a contributor of articles to the *CFIDS Chronicle* as well as to the *National CFIDS Foundation's The National Forum* patient newsletter. Dr. Goldstein had dozens of publications in peer-reviewed journals. Dr. Goldstein had also organized annual international conferences about the neurobiology of CFS and broadened the scope of meetings to include other disorders of regulatory physiology caused by dysfunction of the limbic system.

REMEMBERING DR. JAY GOLDSTEIN (1943-2021)

By Kathy Collett (Twitter: @kathycollett7) – Copyright 2021

This is the article I never wanted to write. It is to acknowledge a brilliant doctor, Dr. Jay A. Goldstein, who has sadly passed away.

In the late 1980's he began to see patients with Myalgic Encephalomyelitis after his wife, Gail Coplin Goldstein, who I believe is a psychologist, suggested he see them because she couldn't help them.

Around the time of the Lake Tahoe outbreak, several U.S. doctors like Drs. Cheney, Peterson, Lapp and Lerner, to name just a few, began to focus on the illness. Dr. Goldstein and Dr. Cheney set up their clinics on the opposite sides of the U.S. Many of these doctors regularly attended conferences held throughout the world and they would share their knowledge. Often the conferences were reported in various newsletters and this was the main way patients stayed informed.

In one newsletter, I was struck by a comment Dr. Goldstein made. He said the Myalgic Encephalomyelitis was too complicated for the human brain to understand. That naturally shocked me, and I felt deflated. I am glad he made the comment though because it made me notice him and later, I bought his book, *The Limbic Hypothesis*, which led him to focus on brain dysfunction and neuroscience. Other book titles are *Betrayal By The Brain*, *Tuning the Brain*, and *A Companion Volume to Betrayal of the Brain* by Katie Courmel.

His clinic was set up to deal with ME and overlapping illnesses. Before long, patients flew to California from around the U.S. and the world and I was one of them. I saw him in 1994 and 1995 because I was inspired by one of his treatments I found in his book. Along with ME, I have Repetitive Strain Injury and Fibromyalgia.

He recommended nitroglycerin patches used for heart treatments to treat pain. He had an excellent knowledge of pharmacology and used drugs in alternative ways. I found if I applied half a patch on my upper arm, I could use my arms for three hours straight. The medication allowed me to attend art classes and, many years later, I got a degree. Previously, the pain would appear within twenty minutes and remain for a week making it impossible for me to use my arms in a repetitive manner.

Thrilled with the result, I then set about alerting patients in Perth, Western Australia about him but it wasn't productive so I then reached out to the support groups in Sydney and Melbourne and they wrote about him in the newsletters. I decided it would be beneficial to have him here in Australia to lecture to doctors and, as it needed funding, I decided to kick it off with a donation and two others offered money, too, but there wasn't enough so it fell through.

Imagine my surprise when someone else decided to hold the inaugural international conference in 1998 in Sydney. She was inspired by my idea to bring an internationally known doctor to Australia and she deliberately left off Dr. Goldstein as a listed speaker upsetting patients and doctors who attended the conference. Dr. Byron Hyde presented Drs. Goldstein's and Mena's brain SPECT scans and I can remember Dr. Lerner saying, "Those brain SPECT scans are spectacular. Have they been published?"

Dr. Goldstein did attend but the organizer still didn't include him. He paid for his own fare and accommodation whereas the invited keynote speaker, Dr. Peter Rowe (he became a professor later) was provided with both. I was stunned when Dr. Rowe asked for and received airfare and accommodation to be included for his wife and child as well. The money would have been better spent on Dr. Goldstein who was prepared to speak and another doctor.

Prior to the conference, Dr. Rowe gave instructions to the organizer not to include Dr. Goldstein. It was obvious he didn't want anyone to deflect from him. The organizer agreed and continued to leave him off at subsequent conferences she arranged for the following years resulting in conferences excluding the brain. The following year, at the Belgium conference in

1999, ME was declared a brain dysfunction illness with a biochemical cause, thereby validating Dr. Goldstein's research.

During the panel discussion at the end of the conference, Dr. Goldstein asked a question. Everyone swung around to see who had asked such a complicated question and Dr. Rowe sat there and rudely shook his head because he didn't understand the question and the brain implication. However, approximately 30 years later, in 2020, Professor Rowe published a paper on brain SPECT scans and decreased blood flow to the brain. Dr. Goldstein and Mena did the same in late 1980's. Professor Rowe did not acknowledge Dr. Goldstein or Mena in the published paper.

Ed. Note: Kathy's experience with Dr. Goldstein can be Googled: The Lost Years Kathy Collett. Dr. Goldstein was the NCF's first medical director. A story about Dr. Goldstein's memorial can be found online entitled, "Travel Deals, Points, Miles, And a Jewish Burial." (<https://www.lubavitch.com/travel-deals-points-miles-and-a-jewish-burial/>)

The following comments were taken from Dr. Jay Goldstein's memorial announcement:

Gail L. Coplin Goldstein (widow of Dr. Goldstein):

"I am his widow. A kinder, more generous man would be hard to find. A scholar, healer, and family man who was both praised and vilified for his groundbreaking research in ME. I believed in him. There were political and social forces that impacted his later years, and much professional jealousy. So sad. I hope those who gave him no credit yet claimed his work as theirs and profited from it have done some good with it. I used to tease him that he was a Talmudic scholar in disguise, always studying and working for the benefit of mankind. Thank you for your kind sentiments."

Byron Hyde, MD IN:

"Dear Gail, I loved your husband like a brother and one of the few in a handful of knowledgeable on M.E. who had actually examined and investigated patients. Most of the CDC and NIH experts have never any significant number of M.E. patients and many of the so-called experts have never investigated even one patient. As you know, Jay had a difficult childhood, and had a long fight with his chronic illness since childhood.

But he was also one of the few persons I have met who I could call a true genius. He was always diminished by the authorities and his real knowledge never listened to by the “experts” at the CDC and NIH who were not experts at all but poorly educated fools, that have unfortunately remained in power in the politics of medicine and never in the science of medicine.

Jay was a very good friend and we collaborated on several patients. He also introduced me to the amazing Dr. Ismael Mena in California which set me onto the study of SPECT brain imaging.

Then, added to his already difficult burdens, Jay had been hospitalized for many years with a degenerative brain disease and he is probably happy to have gone to his final rest. Fortunately, he had a loving and caring wife. In this he was a lucky man.

Jay once got up at a major public meeting in a large San Francisco hotel, when we were together and told the CDC officials there, they were all total idiots. The CDC officials were stunned, but he also received a large clapping from the hundreds of others present. He was correct of course and I would have added Dangerous Idiots who have destroyed any significant advance on the M.E. spectrum of disease for over 30 years. The CDC has created a tragedy we didn't have to add to the already sufficient difficulties with M.E.

When Jay stated that M.E. was a disease of the brain, particularly affecting the central limbic system of the brain, he was correct of course. It is so obvious when you look at an M.E. patient's brain SPECT. All M.E. patients have an injury to the anterior left temporal lobe and the posterior limbic system. The degree of injury usually expands through the brain consistent with the degree of disability. Jay Goldstein was a most wonderful and generous man. His only real luck was to have a wonderful wife and son. He had suffered too much for too long.”

Gail Kansky:

“Dr. Jay Goldstein was a brilliant man who was so friendly and so compassionate. His work helped so many patients. He will never be forgotten by those from the National CFIDS Foundation along with countless others around the world.”

CONCLUSIVE EVIDENCE CONNECTS ALPHA-RADIATION EXPOSURE TO LIVER CANCER

By NCF Medical Committee June 3, 2021 – Copyright 2021

In its on-going research and investigational work, the National CFIDS Foundation has identified a critical connection between chronic alpha-radiation exposure and the development of hepatic/liver cancer.

In 2010, the National CFIDS Foundation identified the presence of internal alpha-radionuclides in its CFIDS/ME patient cohort. SKY analysis subsequently identified chromosomal abnormalities in these same patients. Liquid biopsies then identified the presence of specific cancer proteins in 60% of these patients. Internal alpha-radiation exposure represents a chronic exposure profile for patients.

From the Center for Environmental Health Studies in Boston, “According to the National Research Council’s BEIR V Committee, there is “conclusive” evidence that chronic exposure to alpha-emitters can cause liver cancer in humans.”

Recently, the National CFIDS Foundation provided a \$100,000 research grant to Dr. Jack Wands, a world expert in hepatic/liver cancer at Brown University, for his work on ASPH, a liver enzyme that is generated in hepatic/liver cancer. ASPH positivity has been seen in patients with CFIDS/ME.

According to the Foundation, there is no doubt in our minds at this point that the liver is a key target associated with our research discoveries, both past and present. The late Dr. Yoshitsugi Hokama, pathologist at the University of Hawaii, believed that the liver was of critical importance to the disease process associated with CFIDS/ME. As such, the Foundation is highly optimistic regarding Dr. Wands’ research and the clinical implications of his work that will follow.

Please see our website for continued updates.

“It will never be decommissioned. Radiation levels at Fukushima plant found worse and more lethal than previously assumed.”

~ Dr. Helen Caldicott (tweet)

LIVING WITH CFIDS (The Seashore Metaphor)

By Audrey Sparks – Copyright 2021

I have CFIDS
but you don't
so you might not understand
that this illness keeps me trapped
as though I'm stuck in sand

Knee-deep at the seashore
Shoveling sand against the tide,
failing to make
either moat
or sandcastle,
no matter how hard I've tried



And that tide is relentless!
The tide keeps coming in
And it doesn't matter how exhausted I am,
I can't ever give up
While I'm still stuck
...but I'm nervous
'cause I can't swim

“Long-time ME people, even here in the US, worked hard for years and are being disregarded today because they don't agree with those new organizations whose message is not ME, it's everything thrown in the kitchen sink!”

~ Anna Giuseppa, PWME

ASK BERNIE THE ATTORNEY

By Bernard A. Kansky, Esq. – Copyright 2021

Q. I suffered from Covid-19 during the height of the pandemic. I was able to recover, but I have never regained the energy, endurance and sharpness I had before Covid-19. My symptoms include many of the symptoms which I have since learned are experienced continuously by victims of Chronic Fatigue and Immune Dysfunction Syndrome, a disease which I and several of my acquaintances never before took seriously. The symptoms from which I now suffer include overwhelming body weakness, sleep disorder, shortness of breath, intolerance to certain strong aromas, intolerance to alcoholic beverages, unusual sensitivities to certain foods and medications, fatigue i.e., exhaustion usually made worse by physical activity, recurrent flu-like illness, joint and muscle pain, severe allergies, muscle weakness and muscle stiffness. In addition, I experience anxiety, occasional headaches, dizziness, loss of balance, ringing in the ears, intolerance of bright lights, rapid heartbeat, and on occasion, chest pain as well. What can I do?

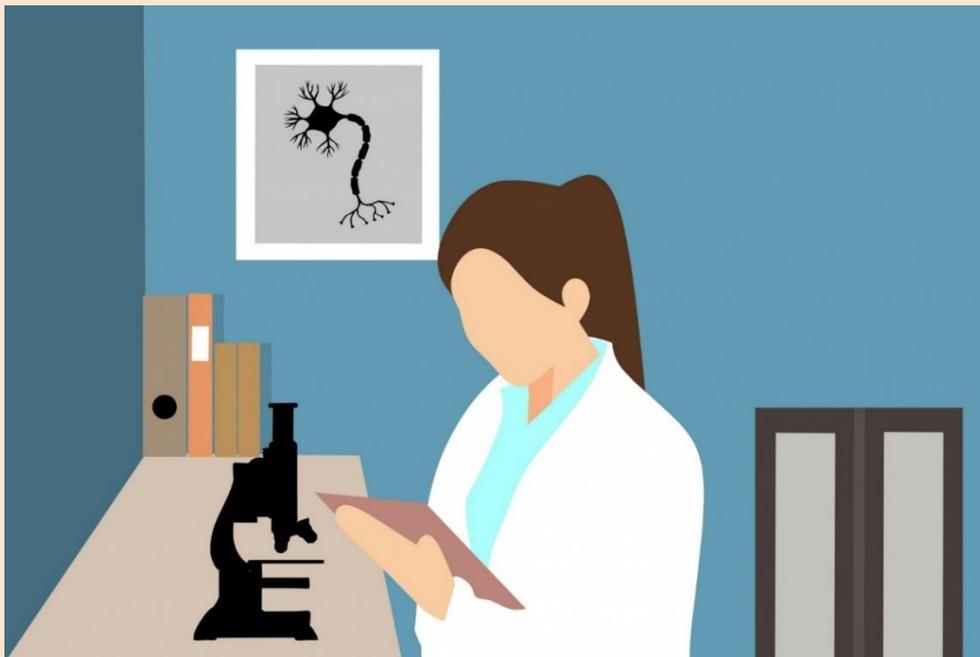
A. The National CFIDS Foundation, Inc. believes it is very close to finding a major treatment for Chronic Fatigue and Immune Dysfunction Syndrome by providing major funding for researchers in the United States and other countries. Recently, the National CFIDS Foundation has already funded nearly a quarter of a million dollars for this research which will include certain designated clinical trials on many long-term victims of CFIDS. What is of great importance to you as a long-haul victim of Covid-19, is that whatever testing and research is found to treat the long-term victims of CFIDS, will also benefit the long-haulers of Covid-19. Much of what is set forth in this article can be found in our recent newsletters which are available at no charge, online, at the National CFIDS Foundation's website. Membership is a voluntary \$10.00 per year. Needless to say, the more funds raised quickly for these researchers and the clinical trials, the sooner that both of these illnesses can be treated and/or cured.

There are some additional steps that should be considered as a long-term Covid-19, "long hauler." If your suffering from Covid-19 and your "partial recovery" has left you totally and permanently unable to engage in any substantial, gainful employment activity so that you are no longer able to work 8 hours a day, 5 days a week, 52 weeks a year, year after year, and are unable to generate a certain minimum income, you should keep a daily diary of your disabling symptoms, be treated by your physician who understands and can prepare in detail, a report of your overwhelming work limitations and how each symptom separately and/or in combination, prevents you from engaging in substantial gainful employment activity. In addition, be certain to get copies of your employer's short-term and long-term disability handbooks and immediately

become thoroughly familiar with each as well as becoming familiar with your earning records on file with the Social Security Administration.

If you have any questions for Bernie, please send a brief letter of inquiry to “Ask Bernie The Attorney,” c/o The National CFIDS Foundation, Inc. 103 Aletha Road, Needham, MA 02492-3931, along with a self-addressed, stamped self-enclosed reply envelope. For Better Health Always!

MEDICAL JOURNAL SUMMARIES



Numeric rating scales show prolonged post-exertional symptoms after orthostatic testing of adults with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, van Campen et al. *Frontiers in Medicine*, Jan 2021.

Researchers from the Netherlands joined together with the U.S.'s John Hopkins University School of Medicine to find the stress of orthostatic intolerance increased the scores of pain, fatigue, and lack of concentration up to seven days later. This seemed to point out that orthostatic stress leads to post-exertional malaise (PEM).

Are there subgroups of chronic fatigue syndrome? An exploratory cluster analysis of biological markers, Asprusten et al. *J Translational Med*, Jan 2021.

This Norwegian team compared genetic markers, diagnostic types, symptoms, and prognosis in teenagers. They found “substantial overlap between clusters” and “no distinct subgroups could be identified.”

In Depth Analysis of the Plasma Proteome in ME/CFS Exposes Disrupted Ephrin-Eph and Immune System Signaling, Germain et al. *Proteomes*, Jan 2021.

The largest proteomics dataset was used to detect proteins and found 19 were extremely different in patients compared to healthy controls. Their careful work seems promising for future work.

Off label use of Aripiprazole shows promise as a treatment for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): a retrospective study of 101 patients treated with a low dose of Aripiprazole, Crosby et al. *J Translational Med*, Feb 2021.

At Stanford and Michigan Universities, the authors found, of 101 patients, 74% found one or more symptoms improved at an extremely low dose but 12% had no help and 14% experienced worsening symptoms or negative side effects. The researchers feel a clinical trial should be held for further investigation.

Insight from Invasive Cardiopulmonary Exercise Testing of Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Joseph et al. *Chest*, Feb 2021.

During exercising, the patients averaged lower right atrial pressure and peak oxygen intake as compared to healthy controls that showed two sorts of peripheral neurovascular dysregulation that seem to contribute to exertional intolerance as well as the peripheral oxygen being impaired.

A SWATH-MS analysis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome peripheral blood mononuclear cell proteomes reveals mitochondrial dysfunction, Sweetman et al. *J Translational Med*, Feb 2021.

These New Zealand researchers identified proteins in 22 blood samples that had decreased abundance relative to those found in healthy controls. These same abnormalities are also found in apoptosis, immune inflammatory problems, and mitochondrial function which have all been found in CFIDS/ME.

Isolation of the effects of alpha-related components from total effects of radium at low doses, Mothersill et al. *International Journal of Radiation Biology*, Dec 2020.

From a team of expert radiation biologists who are examining the mechanisms between low-level radiation exposure and CFIDS/ME. The NCF helped to fund this work. “At sub-lethal doses, survival depends on repair mechanisms.” Internal alpha-radiation is what the NCF discovered in their patient cohort. This paper adds to our understanding of radiation exposure associated with alpha-particles.

A Literature Review of GP Knowledge and Understanding ME/CFS: A Report from the Socioeconomic Working Group of the European Network on ME/CFS (EUROMENE), Pheby et al. *Medicina*, Dec 2020.

A search on MEDLINE helped this group locate surveys of doctors that identified that “a third to a half of all GPs did not accept ME/CFS as a genuine clinical entity and, even when they did, they lacked confidence in diagnosing or managing it.” This ignorance in diagnosis posed a risk to the patient. Indeed, it is exactly what can be expected in the United States although most of the patients believe that there are greater risks than these estimates convey.

A systemic review of nutraceutical interventions for mitochondrial dysfunctions in myalgic encephalomyelitis/chronic fatigue syndrome, Maksoud et al. *J Translational Med*, Mar 2021.

This Australian group of authors tried to find the effectiveness of different nutraceuticals to help the mitochondrial and fatigue problems of patients. These had been tried years ago but patients didn’t achieve significant improvement. Those used were NADH, CoQ10, Acetyl L-Carnitine and Ubiquinol-10. These appeared to be helpful in six out of nine study trials but the

trials were identified to be too limited or their length was too short to prove an effect. Better designed clinical trials are needed in the future. None of these neutraceuticals were found to present any harm.

Hand grip strength and fatigability: correlation with clinical parameters and diagnostic suitability in ME/CFS, Jikel et al. *J Translational Med*, April 2021.

Despite muscular fatigue being part of ME/CFIDS, there's no established clinical way to test for it. This study used repeat maximum handgrip strength (HGS) in 100 patients and 66 healthy controls using an electric dynamometer repetitively. Not only did the patients show significantly lower scores than controls but their recovery ratio was much slower. The more severe the patient, the lower their levels were which means if the tests were done repeatedly over time, it could be a way to objectively show the disease severity.

COVID-19 and post-infectious myalgic encephalomyelitis/chronic fatigue syndrome: A narrative review; Poenaru et al. *Therapeutic Advances in Infectious Disease*, Preprint April 2021.

The comparison of Covid long-haulers to ME/CFS has been written in many articles even though there is no science to intertwine the two afflictions. This article, written by Canadian hospital affiliated physicians, write of the “important similarities” and state, “there is currently insufficient evidence to establish COVID-19 as an infectious trigger for ME/CFS.”

Life-Threatening Malnutrition in Very Severe ME/CFS; Baxter et al. *Healthcare*, April 2021.

These authors explain that those with very severe CFIDS/ME have difficulty swallowing as well as tolerating food due to gastrointestinal problems. They give five case reports where doctors delayed tube feeding since they thought the patients needed psychological help. This can lead to severe malnutrition which can threaten the lives of patients. The authors state that this article “aims to alert healthcare professionals to these realities.”

Altered endothelial dysfunction-related miRs in plasma from ME/CFS patients; Blauensteiner J et. al; *Sci Rep*, 2021 May 19;11(1):10604.

The levels of five microRNAs (molecules which help cells create proteins) were increased in people with ME/CFS compared with healthy controls. These specific microRNAs are all involved in controlling the endothelium (the inner lining of blood vessels), dysfunction of which

can be associated with inflammation that is found in a subgroup of patients. These microRNAs may therefore provide biomarkers and help further characterise endothelial dysfunction in ME/CFS.

Isolation of the effects of alpha-related components from total effects of radium at low doses, Fernando C et al. *Int J Radiat Biol*, 2021 Jan 14;1-14.

Radium is the most common source of alpha radiation exposure to humans and non-human species in the environment but the dosimetry is complicated by the decay chain which involves gamma exposure due to radon daughters. This paper seeks to determine the separate contributions of alpha and gamma doses to the total dose and total direct and non-targeted effect in a fish and a human cell line.

Results: The human cell line showed increased radioresistance when exposed to low doses of alpha-particles. Significant and complex levels of non-targeted effects were induced in progeny of irradiated cells. Funded by the NCF.

Influence of common dietary supplements (curcumin, andrographolide, and d-limonene) on the radiobiological responses of p53-competent colonic cancer epithelial cells; Vukmirovic D et al; *Int J Radiat Biol*, 2021;97(3):341-347.

The main goal of the research was to determine whether commercially available common dietary phytochemical supplements (curcumin, andrographolide, and d-limonene) have radiomodulatory effects on p53-competent human colonic epithelial cells. Results: Curcumin, andrographolide, and d-limonene appeared to not exhibit radioprotective and radiomitigative properties in HCT116 p53^{+/+} cells. D-limonene was found to induce radiosensitization in post-irradiation administration. All three compounds appeared not to modulate the radiation-induced bystander signal production and response in HCT116 p53^{+/+} cells. Funded by the NCF.

Commonalities Between COVID-19 and Radiation Injury; Rios C et. al; *Radiat Res*, 2021 Jan 1;195(1):1-24.

As the multi-systemic components of COVID-19 emerge, parallel etiologies can be drawn between SARS-CoV-2 infection and radiation injuries. While some SARS-CoV-2-infected individuals present as asymptomatic, others exhibit mild symptoms that may include fever, cough, chills, and unusual symptoms like loss of taste and smell and reddening in the extremities (e.g., "COVID toes," suggestive of microvessel damage). Still others alarm healthcare providers

with extreme and rapid onset of high-risk indicators of mortality that include acute respiratory distress syndrome (ARDS), multi-organ hypercoagulation, hypoxia and cardiovascular damage. Researchers are quickly refocusing their science to address this enigmatic virus that seems to unveil itself in new ways without discrimination. As investigators begin to identify early markers of disease, identification of common threads with other pathologies may provide some clues. Interestingly, years of research in the field of radiation biology documents the complex multiorgan nature of another disease state that occurs after exposure to high doses of radiation: the acute radiation syndrome (ARS). Inflammation is a key common player in COVID-19 and ARS and drives the multi-system damage that dramatically alters biological homeostasis. Both conditions initiate a cytokine storm, with similar pro-inflammatory molecules increased and other anti-inflammatory molecules decreased. These changes manifest in a variety of ways, with a demonstrably higher health impact in patients having underlying medical conditions. The potentially dramatic human impact of ARS has guided the science that has identified many biomarkers of radiation exposure, established medical management strategies for ARS, and led to the development of medical countermeasures for use in the event of a radiation public health emergency. These efforts can now be leveraged to help elucidate mechanisms of action of COVID-19 injuries. Furthermore, this intersection between COVID-19 and ARS may point to approaches that could accelerate the discovery of treatments for both.

A high-throughput alpha particle irradiation system for monitoring DNA damage repair, genome instability and screening in human cell and yeast model systems; FKT Stanley et. al; *Nucleic Acids Res*, 2020 Nov 4;48(19):e111.

Ionizing radiation (IR) is environmentally prevalent and, depending on dose and linear energy transfer (LET), can elicit serious health effects by damaging DNA. Relative to low LET photon radiation (X-rays, gamma rays), higher LET particle radiation produces more disease causing, complex DNA damage that is substantially more challenging to resolve quickly or accurately. Despite the majority of human lifetime IR exposure involving long-term, repetitive, low doses of high LET alpha particles (e.g. radon gas inhalation), technological limitations to deliver alpha particles in the laboratory conveniently, repeatedly, over a prolonged period, in low doses and in an affordable, high-throughput manner have constrained DNA damage and repair research on this topic. To resolve this, we developed an inexpensive, high capacity, 96-well plate-compatible alpha particle irradiator capable of delivering adjustable, low mGy/s particle radiation doses in multiple model systems and on the benchtop of a standard laboratory. The system enables monitoring alpha particle effects on DNA damage repair and signalling, genome stability pathways, oxidative stress, cell cycle phase distribution, cell viability and clonogenic survival using numerous microscopy-based and physical techniques. Most importantly, this method is

foundational for high-throughput genetic screening and small molecule testing in mammalian and yeast cells. Funded by the NCF.

Radon exposure is rising steadily within the modern North American residential environment, and is increasingly uniform across seasons; FKT Stanley et. al; *Sci Rep*, 2019 Dec 3;9(1):18472

Human-made buildings can artificially concentrate radioactive radon gas of geologic origin, exposing occupants to harmful alpha particle radiation emissions that damage DNA and increase lung cancer risk. We examined how North American residential radon exposure varies by modern environmental design, occupant behaviour and season. 11,727 residential buildings were radon-tested using multiple approaches coupled to geologic, geographic, architectural, seasonal, and behavioural data with quality controls. Regional residences contained 108 Bq/m³ geometric mean radon (min < 15 Bq/m³; max 7,199 Bq/m³), with 17.8% \geq 200 Bq/m³. Pairwise analysis reveals that short term radon tests, despite wide usage, display limited value for establishing dosimetry, with precision being strongly influenced by time of year. Regression analyses indicates that the modern North American Prairie residential environment displays exceptionally high and worsening radon exposure, with more recent construction year, greater square footage, fewer storeys, greater ceiling height, and reduced window opening behaviour all associated with increased radon. Remarkably, multiple test approaches reveal minimal winter-to-summer radon variation in almost half of properties, with the remainder having either higher winter or higher summer radon. This challenges the utility of seasonal correction values for establishing dosimetry in risk estimations and suggests that radon-attributable cancers are being underestimated.

Reprint of: Deciphering and simulating models of radiation genotoxicity with CRISPR/Cas9 systems;

Vukmirovic D et. al; *Mutat Res*, Jul-Sep 2020;785:108318.

This short review explores the utility and applications of CRISPR/Cas9 systems in radiobiology. Specifically, in the context of experimentally simulating genotoxic effects of Ionizing Radiation (IR) to determine the contributions from DNA targets and 'Complex Double-Stranded Breaks' (complex DSBs) to the IR response. Funded by the NCF.

“Given the clear discrepancy between actual data measured in the field and dose effects generated using databases populated mainly with acute lab based experimental data, it is imperative that we strive to develop meaningful holistic systems for protection of those living in contaminated ecosystems.”

~ Dr. Carmel Mothersill, McMaster University

IN MEMORIUM

The following names have been added to our Memorial List available on our website. Our sincere condolences to the friends and families of all those on our Memorial List.



Robert Barshied, 69, passed away peacefully on February 23, 2018 in Palm Coast Florida. Bob was a loving father, husband, and grandfather. He was a welcomed friend and generous contributor to all he met. Bob obtained his bachelor's degree with honors from Clarkson University and master's degree from Rensselaer Polytechnic Institute. His education allowed him to blend his love of the outdoors and his work. Bob was especially proud of his work preparing the facilities for the 1980 Winter Olympics in Lake Placid for Team USA. Bob was an avid sportsman and golfer. He will be missed by all that had the pleasure of knowing him. He is survived by his beloved wife Kathleen, his son Scott, brother Willis, and three cherished grandchildren.

Robert “Bob” Benson died in his early 80’s following complications from a fall in 2021. He attended Clemson University on a basketball scholarship, owned a soccer team, the Carolina Lightnin’, which won a championship. He also owned a World Tennis Team and ran his own business for decades. He was a lifelong fan of the Pittsburgh Steelers and the Pirates. He lived for many years with CFIDS/ME and upon his death his obituary recommended monetary funds be donated to the NCF. His death left many in sorrow including his wife Marjory, his son Michael and his three grandchildren.

Amy Haskins Croyder, 57, found peace on November 21 after bravely battling CFS/ME for over thirty years. She is survived by her beloved twins, Logan and Nora Bahns; her mother, three sisters, and her sister-in-law. Amy was tender-hearted, tenacious, a perfectionist. Before

becoming ill at age 21, she was a star athlete, a fantastic gymnast and runner. She worked with the intellectually disabled, was a strong writer, and an even better communicator. She was quick to offer support, praise and positivity. There was no one she was unwilling to help. She was a rare combination of true grit and open heart and will be terribly missed. Her smile, her hugs, her laughter will forever be missed by her family and friends.

Steven Eddy, 66, died in the early hours of the morning of February 13, 2021. He lived in Mahomet, Illinois. His sister told a PWME friend that he had been cremated and his ashes would be buried near his mother's grave in Mt. Olive Cemetary. (Source: Debbie S. in Kemo)

Ian John Fulton, 38, passed away in June of 2020. He was sick with ME since he was a child. He lived in a small village in the UK with his parents, David and Elizabeth. He was a wonderful friend to many people. He was cremated and the many friends who he had were so sorry to see his life ended so soon. Although he suffered from ME, when others tried to find ways to help him improve, they ended up realizing that there was nothing that would help him. He did find others with ME online that he conversed with. He is missed by members of his family as well as friends.

Patrick Selby Johnson, 48, suffered for years until his death on December 29, 2020. He was born and lived in Canada where his intelligence was recognized as a child when he took apart toys and reassembled them out of curiosity. After a trip overseas in his 20's, he worked as a computer programmer and designer of web pages and displayed his artistic talents in many ways until CFIDS/ME no longer allowed him to work. Pat gave technical support to those on Phoenix Rising as well as friendship to the members. He is remembered and missed by so many whom he helped as well as by his family and friends.

Theodore Samuel "Teddy" Katz died on New Year's Day of 2021 after suffering for over 15 years from cancer following CFIDS/ME. His obituary, from the Tuscaloosa News, stated that "Teddy was literally hell on wheels when he was young, nicknamed 'Hot Rod Teddy' for his love of rebuilding and drag racing cars as a teenager." Teddy loved music and learned to play the drums in high school. He went to the University of Alabama and became a DJ at the radio station there. He was a local sales manager for a radio station but soon became the General Manager of five iHeart radio stations. In 2011, his University named him an "Outstanding Alumni." He married Lisa just a year later. He worked until he was no longer able to due to his illness. Joining Lisa in grief was his mother, Dr. Elaine Katz, his siblings, nieces, and nephews.

Faustine Nogherotto, 31, was a famous singer in her native France until CFIDS/ME took her life. Faustine was featured on television as well as a singer for audiences with her beautiful soprano voice. She was dismissed by the medical practitioners just as so many are in France to this day but continued on with her career with determination despite the extreme pain and other severe ME symptoms. She helped to raise money for ME awareness. She said, “For five years, I have been living in hell” and she missed so much of what she dreamed of doing in the future. ME took her life in January of 2021. She is missed by so many fans along with her personal friends. (Source: Jacquie Wilson)

Elizabeth Derryan Paul, PhD lived in England and had CFIDS/ME for decades. She volunteered as secretary for a support group until it closed in 2013. Her lectures and appearances helped advocate for the disease. She helped so many patients in ways such as having them meet at her home for classes on therapeutic yoga. She was an inspiration to many patients and is missed by them. She worsened after retirement and had to move into a nursing home where she eventually died in February of 2021.

Elizabeth C. “Libby” Potter, 67, passed away in November of 2019. Libby lived in and graduated college from Massachusetts and taught school in Danvers. She was active in a chapter of the Daughters of the American Revolution and on the board of a state organization for CFIDS/ME. She helped arrange for a major presentation on ME/CFIDS for the state nurses at a health conference. Libby is survived by one sister and three brothers as well as many other relatives and friends who miss her including those who, like she did, suffer from CFIDS/ME.

Lisa Brinkley Powell, 55, of Morganton, North Carolina, died in March of 2020. Lisa had been a dental hygienist and helped to begin the Smart Smiles Program in the Burke County Schools. Lisa was happily married and had two sons. She is survived and mourned by her husband, Lance, as well as her mother, sons, a brother, and many other relatives and friends.

Carol Sieverling died in the first month of 2021 in a hospital. She had stage 4 myeloma and was receiving chemo and radiation. Carol had CFIDS/ME for many years and led a support group in the Dallas/Fort Worth area in Texas. Her sister spent the last few months of Carol’s life with her. Carol was a patient of Dr. Paul Cheney for years but her illness, of course, could not be helped. For her memorial, Dr. Cheney wrote, “I will always remember her deep caring of the less fortunate and the misunderstood.” Years earlier, the Dallas/Fort Worth CFIDS/FM Support Group gave a plaque to Carol that read, “For all of the times in pain and feeling lost,

you were there on the phone. For all of us that needed answers, you were the one that showed us the path. For all of us who owe you so much, thank you is not nearly enough.” (Source: fellow patient K.S. and online memorial)

Lindsay Sturm, 32, died in December of 2020 after suffering with CFIDS/ME for 7 years. Lindsay was an animal lover and had thought about becoming a veterinarian but changed her mind and studied cognitive neuroscience at Columbia University. When she first got sick, she saw multiple doctors but they could not diagnose her, so she did the research on her own and diagnosed herself. The last two years of her life found her housebound and often bedbound until she died in her sleep.

DONATIONS

The National CFIDS Foundation is immensely grateful to each person listed below. Every penny of their donation has gone to fund research that will eventually help us all live our lives better than ME/CFIDS has allowed thus far. Each donation to the NCF is tax deductible to the full extent allowed by US federal law as our charity is a federally approved 501(c)(3).



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