AONM's Webinar ~ Long COVID from a Clinical Perspective with Professor Lambert on February 22nd 2023 attracted a huge audience.

We received so many questions it was impossible for them to all be addressed on the night.

Professor Lambert has been extremely generous in answering questions since the webinar and allowing us to make them accessible to all.

Q. Did Dr Lambert's group look for VZV DNA/PCR reactivation?

A. WE HAVE SEEN VZV REACTIVATION IN THE SETTING OF ACUTE COVID. I AM SEEING PEOPLE WITH MULTIPLE RELAPSES OF ZOSTER/VZV. I AM ALSO SEEING PATIENTS WITH LONG COVID WHO ARE IMMUNOSUPPRESSED, GET RELAPSES OF HERPES, ZOSTER, AND ALSO GETTING NEW EBV INFECTIONS. MAYBE THEY ARE MORE 'PRONE' TO SUCH INFECTIONS BECAUSE THEY ARE IMMUNOSUPPRESSED?

Q. Curious about the findings on alcohol use. This seems odd given many C19 patients (similar to ME/CFS patients) report alcohol intolerance as a symptom, with alcohol use causing significant exacerbation of other symptoms and/or crash. Do you have any observations on this?

A. THE DATA IS THE DATA. PATIENTS IN OUR STUDY REPORTED THEY WERE 'TURNING TO ALCOHOL' TO COPE WITH LC SYMPTOMS. THE STUDY DID NOT SAY THEY ARE DRINKING EXCESSIVE AMOUNTS OF ALCOHOL. PATIENTS WITH BRAIN INJURY, CHRONIC LYME, LONG COVID ARE EXTREMELY SENSITIVE TO THE EFFECTS OF ALCOHOL. WE KNOW THAT. SO ALCOHOL INTOLERANCE AND TURNING TO ALCOHOL TO COPE ARE NOT MUTUALLY EXCLUSIVE.

Q. Is there any research looking to see if the Covid virus can become latent in the ganglia, in the same way that the VZV virus can, possibly causing ongoing immune activation?

A. COVID IS A CORONAVIRUS. THERE ARE LOTS OF STUDIES ON CORONAVIRUSES AND THEY ARE NOT LIKE DNA VIRUSES WHERE THEY INCORPORATE INTO THE BODY AND STAY IN THE SYSTEM FOR LIFE. SO, APPLES AND ORANGES. COVID 19 IS NOT A HERPES VIRUS. BUT THERE IS EVIDENCE OF 'PERSISTENCE 'IN THE BRAIN FOR LONGER PERIODS MAYBE THREE MONTHS, WHEN THE VIRUS CAN NO LONGER BE DETECTED IN THE OTHER TISSUES OF THE BODY

Q. Is there any evidence of disturbance to the Gut Microbiome and either a lack of available nutrients for the body or changed mood/mental function?

A. THERE IS CLEAR EVIDENCE OF GUT MICROBIOTA DISRUPTION. AND THERE IS DATA THAT REPAIRING THE GUT MICROBIOME CAN IMPROVE SYSTEMIC SYMPTOMS SUCH AS PAIN AND BRAIN DYSFUNCTION.

Q. I'd be interested to know whether any of the cohort tested for Lyme and co and what the results were?

A. I TEST ALL PATIENTS WITH LONG COVID FOR LYME. BUT AS YOU KNOW THE LYME ANTIBODY TEST IS POORLY SENSITIVE. TO DATE, ONLY A COUPLE TESTED POSITIVE SO A RARE EVENT. HOWEVER, I HAVE LOTS OF LYME PATIENTS I THOUGHT 'CURED' ON TREATMENT, AND NOW WITH COVID, THEY HAVE RELAPSE OF SYMPTOMS, SO MAYBE THE LYME WAS NOT CURED, AND JUST 'SUPPRESSED' BY TREATMENT, AND COVID (WHICH CAUSED DROPS IN LYMPHOCYTE COUNTS) HAS CAUSED AN IMMUNODEFICIENCY AND REACTIVATION OF LYME?

Q. Are there any links to Air (& Water) pollution?

A. I THINK ANYTHING THAT DAMAGES THE IMMUNE SYSTEM CAN ADD TO THE PROBLEM

Q. Are studies of a combined cohort or Long Covid-CFS(ME) being conducted now or is it just long covid?

A. LOTS OF PEOPLE WITH PRE-EXISTING ME/CFS ARE BEING HIT WORSE WITH COVID/LC, AND GETTING RELAPSE OF SYMPTOMS

Q. Many long covid patients report feelings of pressure in the brain, especially when 'overdoing' things. Some describe a twisted feeling. Is this related to inflammation?

A. THERE APPEARS TO BE 'HEAD PRESSURE' RATHER THAN A HEADACHE. LIKE A VICE SQUEEZING THE BRAIN, AND GETS WORSE WHEN THEY OVERDO IT.

Q. Has there been any improvement with things like low dose naltrexone (LDN)?

A. I PRESENTED ON LOW DOSE NALTREXONE. SEE MY SLIDE SET AND THE PUBLICATION BY BRENDAN O KELLY ET AL <u>https://pubmed.ncbi.nlm.nih.gov/35814187/</u> IT WORKS TO HELP CHRONIC LYME PATIENTS AND OTHER CONDITIONS, AND PILOTS SHOW IT HELPS LC. MORE DEFINITIVE STUDIES ARE NEEDED.

Q. Do you think ARVs could be repurposed? Either due to ARV or AV action? Would it be worth a trial?

A. ARV'S WORK FOR RETROVIRUSES. THERE IS NO EVIDENCE IN PATIENTS WHO ARE HIV POSITIVE

Q. Long Covid rehab programmes / courses out there still purport deconditioning theory. How do we stop this? (Possibly come mainly from, but not solely, fitness industry).

A. THIS IS NOT A DISEASE OF DECONDITIONING, AND 'GRADED EXERCISE' IS THE WRONG STRATEGY. MAKES YOU CRASH.

Q. Very distinctive from ME/CFS or big, if not 100%, overlap?

A. SEE THE STUDIES AND BRAIN SCANS FROM ME/CFS/LONG COVID/PTLDS-CHRONIC LYME.... THERE ARE LOTS OF SIMILARITIES

Q. What are the nerve-blocking medications being used or tried for treating COVID. Would the low dose naltrexone used for Lyme also be useful for COVID? What treatments are most useful for addressing the central brain inflammation and damage?

A. ELAVIL, NEURONTIN OTHER NERVE BLOCKERS WORK BUT ALSO BLOCK THE BRAIN AND WORSEN BRAIN FOG. SO I USE LDN WHICH HAS ANTI-INFLAMMATORY AND IMMUNE MODULATING EFFECTS. MANY PATIENTS FIND A REDUCTION IN NERVE PAIN AND IMPROVEMENTS IN JOINT PAIN AND BRAIN FOG FOLLOWING THE INTRODUCTION OF LDN OVER A PERIOD OF TWO MONTHS OR MORE. NO QUICK FIXES.

Q. Hi Jack, do you have any recommendations for correcting dysregulation of the nervous system?

A. RETRAIN THE BRAIN. REBALANCE THE SYMPATHETIC/PARASYMPATHETIC SYSTEM. THERE ARE BREATHING EXERCISES AND OTHER. ALSO, VAGAL NERVE EXERCISES, CONSIDER TRANSAURICULAR VAGAL NERVE STIMULATION/MACHINES.

Q. Is brain signalling at synapses halted, blocked, or slowed down? Or plasticity altered re-mapping?

A. PET SCANS SHOW HYPOPERFUSION DEFECTS. LACK OF BLOOD SUPPLY. BUT PROBABLY ALSO 'AUTO IMMUNITY AND INFLAMMATION'.

Q. Is there a test for Fibromyalgia, which seems to have many similar symptoms?

A. FIBROMYALGIA IS A TERM COINED BY RHEUMATOLOGISTS WHO SAY IF YOU HAVE PAIN ALL OVER AND NO ALTERNATIVE DIAGNOSIS, THEY YOU HAVE FIBROMYALGIA. I CALL IT HURT ALL OVER SYNDROME. IT IS NOT A DIAGNOSIS. IT IS A DESCRIPTION OF SYMPTOMS. THE QUESTION IS, WHAT CAUSES 'FIBROMYALGIA', WHAT TRIGGERS FIBROMYALGIA? I HAVE MANY PATIENTS WITH ALL SORTS OF SYMPTOMS, AND PAIN ALL OVER, BEING TOLD YOU DON'T HAVE LC YOU HAVE FIBROMYALGIA. BAD MEDICINE I WOULD SAY.

Q. Any studies done on lactoferrin or pine bark extract?

A. LOTS OF THEORETICAL TREATMENTS THAT COULD HELP. BUT WHERE ARE THE STUDIES? RATHER THAN DOING STUDIES TO SHOW BENEFITS OF TREATMENT PEOPLE ARE BEING SENT TO ONE SPECIALIST AFTER ANOTHER AND GETTING ONE TEST AFTER ANOTHER. WE NEED MORE FOCUS ON POSSIBLE TREATMENTS TO IMPROVE. I PROPOSED A STUDY OF LDN IN IRELAND AND WAS 'SHOT DOWN'. IT APPEARS TO BE ONE OF THE FEW TREATMENTS THAT IS SHOWING TO BENEFIT PEOPLE. BUT MY CLINICAL OBSERVATION IS IT HELPS 80 PERCENT, BUT NOT 100%. NO QUICK FIX. Q. Is anything happening with the episode-genome when people get Long Covid?

A. NOTHING PUBLISHED THAT I HAVE SEEN.

Q. Is any parasite testing done on people with Long Covid?

A. PARASITES DON'T CAUSE LONG COVID OR DON'T CAUSE THE SYMPTOMS OF LONG COVID. PEOPLE WHO ARE IMMUNOCOMPROMISED ARE MORE PRONE TO ACQUIRE PARASITES OR REACTIVE DORMANT INFECTIONS IN THEIR SYSTEM. SO REPAIR THE IMMUNE SYSTEM AND THE PARASITE PROBLEM WILL SORT ITSELF. PEOPLE WITH HIV AND AIDS ARE MORE LIKELY TO GET CERTAIN PARASITIC INFECTIONS. ONCE YOU TREAT THE HIV AND THEIR IMMUNE SYSTEM RETURNS TO NORMAL, THESE PARASITIC INFECTIONS DO NOT OCCUR OR RESOLVE THEMSELVES.

Q. Does 5 HCT (sp?) help with the depressive side?

A. SLEEP DISTURBANCES ARE CAUSED BY BRAIN INFLAMMATION. PSYCHOLOGICAL DISTURBANCES ARE CAUSED BY BRAIN INFLAMMATION. COVID /LC CAUSES BRAIN INFLAMMATION. FIX THE BRAIN INFLAMMATION. LDN HELPS WITH BRAIN INFLAMMATION. MELATONIN IS WHAT I CALL A 'SLEEP HORMONE'. IT REGULATES YOUR SLEEP. 5 HYDROXYTRYPTOPHAN ALSO HELPS REGULATE YOUR SLEEP PATTERN. THEY CAN BE HELPFUL WHILE THE BRAIN IS REPAIRING.

Q. Would high dose Omega3 help repair neuro damage?

A. NOT SURE

Q. What would you do for Long Covid patients in heart failure and those with persisting balance problems?

A. HEART COMPLICATIONS ARE RARE, THANK GOD. PATIENTS OFTEN GET SYMPATHETIC / PARASYMPATHETIC IMBALANCE AND IVABRADINE, A DRUG USED FOR HEART FAILURE, SEEMS TO BE BETTER THAN 'BETA BLOCKERS' IE INDEROL. I AM CONCERNED THAT SOME OF THE HEART COMPLICATIONS SEEN TODAY ARE SIDE EFFECTS OF THE COVID 19 VACCINES, ESPECIALLY PERICARDITIS ETC.

Q. Why does NICE not accept these publications?

A. THE POLITICS OF LC PUZZLE ME. THEY SAY THEY ARE WILLING TO CHANGE ONCE THERE IS NEW SCIENCE. BUT THEY DON'T KEEP UP WITH THE NEW SCIENCE. THE IRISH LONG COVID EXPERT GROUP IS A PRIME EXAMPLE OF PUTTING TOGETHER A PLAN THAT IS NOT FIT FOR PURPOSE, AND IGNORING THE NEW SCIENCE THAT HAS DEVELOPED/BEEN IDENTIFIED OVER THE LAST TWO YEARS. THEY REPEATEDLY SAY WHEN NEW SCIENCE BECOMES AVAILABLE, THEY WILL TAKE IT ON BOARD. THEY ARE TAKING NOTHING ON BOARD. THEY ARE A SINKING SHIP, DEFENDING THEIR OUTDATED STRATEGY.

Q. Given that some cases of Long Covid may be due to reactivation of latent virus and that many of these are herpes viruses, would you consider that standard antiviral treatment such as Acyclovir might be a useful part of the management? if so, which agents and for how long?

A. WHEN PATIENTS ARE GETTING SYMPTOMS THAT I THINK MAY BE DUE TO REACTIVATION OF HERPES VIRUSES, I ADVISE VALTREX 500MG TO 1000MG TEMPORARILY, UNTIL THE IMMUNE SYSTEM IS REPAIRED. HOWEVER, THIS DOSE WORKS FOR HSV AND VZV, BUT NOT FOR CMV AND EBV, WHICH MAY ALSO BE BEING REACTIVATED AND CONTRIBUTING TO SYMPTOMS.

Q. Is central sleep apnea always breath related? I often wake with shaking emanating from my chest accompanied by deep palpitations, disturbed vision. I see others with the same on forums - could this be central sleep apnea?

A. THE PET SCANS OF THE BRAIN SHOW HYPOPERFUSION DEFECTS IN THE POSTERIOR PART OF THE BRAIN. THAT IS WHERE THE RESPIRATORY CENTRE IS LOCATED. IT'S IN THE SAME PART OF THE BRAIN IDENTIFIED IN THESE PET SCANS. THUS SOME OF THE 'AIR HUNGER' THAT PATIENTS EXPERIENCE, IN FACT MOST OF IT, IS CENTRAL SLEEP APNEA. AS THERE IS AN 'ALLERGIC' COMPONENT TO LONG COVID, SOME PATIENTS, THE MINORITY, HAVE A FLARE UP OF THEIR ASTHMA, PROBABLY HISTAMINE/MAST CELL MEDIATED.

Q. Every symptom you discuss is the same as those reported by people with vaccine-induced LC. Is the spike key?

A. SPIKE IS BEING IMPLICATED AS PART OF THE PROBLEM. AUTOIMMUNITY POST COVID TO THE SPIKE PROTEIN THAT IS STILL PRESENT IN THE TISSUES AND THE IMMUNE SYSTEM IS ATTACKING. INTERESTINGLY, LOOK AT MY SLIDE SET, NATTOKINASE MAY BE TARGETTING THE SPIKE PROTEIN

Q. Why do some patients feel better during an acute second infection? My brain fog and fatigue went away for during my second and third infections during the acute phase while I was testing positive.

A. MOST OF LONG COVID IS 'IMMUNOLOGICAL'. UNPREDICTABLE. I HAVE SOME PEOPLE MUCH WORSE AFTER A SECOND HIT OF COVID OR THE COVID19 VACCINE; AND I HAVE SOME PEOPLE WITH IMPROVED SYMPTOMS FOLLOWING ANOTHER COVID19 INFECTION OR ANOTHER COVID19 VACCINE.

Q. How do you suggest managing POTS if beta blockers etc have unwanted central effects? Thanks for all this information.

A. POTS IN LC CAUSES UNEXPLAINED TACHYCARDIAS, AND BRADYCARDIAS, AND INCREASED AND DECREASED BLOOD PRESSURE. FLUCTUATING UP AND DOWN. BETA BLOCKERS DROP YOUR BLOOD PRESSURE AND DROP YOUR HEART RATE. MAYBE NOT A GOOD STRATEGY IF YOU HEART RATE IS DROPPING TO 37 AS SOME OF MY PATIENTS HAVE EXPERIENCED. BETTER TO REPAIR THE 'BRAIN' SIGNALLING THAT IS CAUSING THE POTS. AND IVABRADINE, THAT HAS A DIFFERENT MODE OF ACTION, MAY BE A BETTER OPTION. BUT RETRAINING THE BRAIN IS THE BEST OPTION.

Q. Is Vaccine-induced long covid a recognised medical term now and if so is it the spike protein crossing the blood brain barrier that is causing similar symptoms to long covid from infection

A. I HAVE NOT SEEN ANY RECOGNITION. WE NEED TO RECOGNISE VACCINE-INDUCED LONG COVID. WOULD BE NICE TO GET A SERIES OF PET SCANS ON PATIENTS WITH COVID 19-INDUCED VS VACCINE-INDUCED LONG COVID SYMPTOMS. I PREDICT THE SAME PET SCAN ABNORMALITIES; BUT ALL SPECULATION, AS NO ONE SEEMS TO BE DOING STUDIES. MOST OF MY COLLEAGUES ARE REFUSING TO PRESCRIBE LDN, OR, EVEN WHEN THEY SEE PATIENTS GETTING BETTER ON LDN, TELLING THEM TO STOP IT. PUZZLING. WHY?

Comment: A Cardiologist in Cavan General Hospital wanted to admit me to a psychiatrist ward when I presented with heart palpitations!!

I ASK THIS QUESTION ON ALL PATIENTS I SEE WITH LONG COVID. 50% HAVE BEEN OFFERED A PSYCH EVALUATION, OR OFFERED ANTIDEPRESSANTS, OR ANTI-ANXIETY MEDS. AS IT'S ALL PSYCHOSOMATIC ACCORDING TO 'THEM'. 'THEY' HAVE NOT DONE A PUBMED SEARCH AND LOOKED AT THE STUDIES OF PET SCAN ABNORMALITIES IN LONG COVID. I FIND THIS UNACCEPTABLE. BUT THEN AGAIN, GPS HAVE NO GUIDANCE FROM THE IRISH HEALTH EXECUTIVE, ALTHOUGH THEY SAY, (SINCE I MET WITH THEM IN SEPTEMBER 2022) THEY ARE LIASING WITH THE IRISH COLLEGE OF GPS AND DEVELOPING GUIDELINES FOR THE GPS TO MANAGE LC PATIENTS. WHERE ARE THOSE GUIDELINES?

Q. 'I made a 75% recovery from Lyme, now have Long Covid 1 year, would you advise revisiting treating Lyme?

Q. IF YOU HAVE GONE BACKWARDS, TREATMENT WITH ANTIBIOTICS THAT WORKED BEFORE SHOULD BE A LOGICAL NEXT STEP.

Q. When can we expect some form of testing of Long Covid patients with biomarkers? It would really help to counter the tendency of some to see Long Covid as " psychosomatic ".

A. UNFORTUNATELY, SO MANY DIFFERENT TARGETS OF LC, DIFFERENT ORGANS. SOME HAVE PAIN SYNDROMES. SOME HAVE BRAIN FOG. SOME HAVE CRASHING. SOME HAVE BRAIN FOG. SOME HAVE ALL OR JUST SOME. SO PROBABLY NO ONE 'MARKER' WILL BE DEVELOPED. BUT IF YOU WERE QUITE HAPPY AND HEALTHY AND GOT COVID AND NOW, THREE MONTHS LATER, YOU HAVE ALL OF THESE SYMPTOMS, IT IS LONG COVID. MAKE IT A RECOGNISABLE CONDITION, AND MAKE IT SUPPORTED BY THE HSE, BY DISABILITY, BY INSURANCE COMPANIES. AND PAY THOSE WITH LC TO GET BETTER AND GIVE THEM FREE SUPPORTIVE MEDICINES TO ALLOW THEM TO RECOVER (LDN, MELATONIN, NAC, HBOT) AS IT IS IN THE INTEREST OF THE GOVERNMENT AND HSE TO GET THEIR STAFF BACK TO GOOD HEALTH AND BACK ON THE JOB. **Comment:** The work problem is performance management and goals - expectations that are no longer achievable. That leads to resignation or dismissals.

A. LONG COVID PREDISPOSES YOU TO CRASHING. YOU NEED TO PACE, AND NOT PUSH. STILL THE 'TRADITIONAL' MEDICAL SOCIETY TELLS YOU TO PUSH, GRADED EXERCISE. AND ANY KIND OF PUSHING CAN CAUSE YOU TO CRASH. IE TOO MUCH EXERCISE, TOO MUCH EMOTIONAL STRESS, TOO MUCH INTELLECTUAL STIMULATION (LOOKING AT COMPUTER TOO MUCH....TOO MUCH CNS INPUT) THIS NEEDS TO BE RECOGNISED. AND PEOPLE SUPPORTED, NOT DISMISSED FROM JOB.

Q. How would I know if my HSV is reactivated? I'm not getting any cold sores.... But I have most of the other symptoms you've mentioned.

A. YOU COULD BE REACTIVATED WITH EBV OR CMV. WHICH ARE ALSO HERPES VIRUSES. ALL OF THE ONES MENTIONED ABOVE ARE HERPES VIRUSES.

Q. I have worked a lot with medicinal mushrooms to improve symptoms of long Covid, do you use any in your practice?

A. THESE AGENTS HAVE 'NEURO' ACTIONS SO THEY MAKE SENSE IN THEORY. STUDIES NEED TO BE DONE. AND THOSE WITH CLINICAL EXPERIENCE USING THESE AGENTS NEED TO PUBLISH THEIR RESULTS.

Q. How much overlap with ME/CFS do you see? Approach to pacing and symptom control seem similar.

A. I AM NOT HAPPY WITH ME/CFS/FIBROMYALGIA AS STANDALONE DIAGNOSES. THERE MUST BE SOMETHING THAT PRECIPITATES THESE CONDITIONS. THESE CONDITIONS HAVE BEEN CALLED POST INFECTIOUS, POST VIRAL. WHAT VIRUS? COVID19 IS A VIRUS. I THINK THEY ARE PART OF THE SAME UNDERLYING PATHOPHYSIOLOGY. THUS, THE NEED FOR NATIONAL CENTRES TO MANAGE ALL OF THESE CONDITIONS. COMPLEX NEUROPSYCH NATIONAL CENTRES FOR SUPPORT AND NEURO REHABILITATION. LONG COVID LONG LYME CFS/ME

Comment: Into three years of being housebound and bedbound from vaccine-induced long covid and just starting LDN this month. Hoping it will give me back some functionality.

A. HOPE SO. ALSO ADD THE OTHER THINGS, MELATONIN, NAC 600MG TWICE DAILY AND OTHER SUPPLEMENTS. NO ONE SINGLE TREATMENT WILL GET YOU BETTER.

Comment: I had Coxsackie reactivation post-acute covid. No-one knew how to help that.

A. CHRONIC VIRUSES REACTIVATE WHEN YOUR IMMUNE SYSTEM IS LOW. REPAIR YOUR IMMUNE SYSTEM AND PUT THOSE VIRUSES 'BACK INTO THEIR CAGES'.

Q. I suffered a severe allergic reaction to vaccine leaving me with severe acquired asthma, vaccineinduced Long Covid , dysautonomia and postural tachycardia syndrome all confirmed before contracting Covid 3 times .

YES. PART OF LC IS DAMAGED LYMPHOCYTES AND HISTAMINE/MAST CELL DYSFUNCTION/ LYMPHOCYTES CONTROL YOUR IMMUNE AND ALLERGIC IMMUNE SYSTEM. I THINK THEY HAVE TAKEN A 'HIT'. LDN HELPS REPAIR THE IMMUNE SYSTEM AND THE LYMPHOCYTES. ANTIHISTAMINES, HERBAL PRODUCTS TO REPAIR THE HISTAMINE/MAST CELL DYSFUNCTION SEEM LIKE PLAUSIBLE TREATMENTS. NOTHING PROVEN

Q. I am 21 months into recovery and relapse frequently. Dependent on respiratory, heart and neurological medication to get through each day. Thoughts on IVIG treatment to treat neurological and PEM Symptoms?

A. AS STATED BEFORE, IVIG HAS BEEN USED FOR TRANSVERSE MYELITIS, GUILLAIN-BARRÉ, OTHER NEUROLOGICAL SYNDROMES. PROBABLY A GOOD IDEA, BUT STUDIES NEEDED. IN THE MEANTIME, I WOULD SELECTIVELY ADVISE.

Q. You haven't mentioned diet yet - any thoughts on this?

A. I DID MENTION DIET. SEE MY SLIDE ON PROBIOTICS, KEFIR. YOUR GUT IS YOUR IMMUNE SYSTEM/THE MICROBIOME. SO REPAIR THE MICROBIOME. ITS PART OF THE SOLUTION.

Q. I know people who have been vaccinated but say they have never had Covid, yet have a lot of Long Covid symptoms, is this possible?

A. LONG COVID IS IMMUNOLOGICAL. VACCINES ARE IMMUNOLOGICAL PRODUCTS. SOMETIMES THEY STIMULATE THE 'WRONG' IMMUNE SYSTEM. ALSO, MAYBE THOSE WHO GET VACCINE-INDUCED COVID MAY HAVE HAD A PREVIOUS ASYMPTOMATIC COVID19 INFECTION. WE DON'T KNOW. BUT CLEARLY THERE ARE SOME PEOPLE GETTING VACCINE-INDUCED LONG COVID WHO NEVER HAD A PRIMARY COVID19 INFECTION.

Comment: Lions Mane mushroom can repair neurons I have read. I'm going to try it.

A. I HAVE USED LIONS' MANE FOR CHRONIC LYME. THEORETICALLY COULD HAVE BENEFIT IN LC

Q. You've mentioned there are protocols for treatment to reduce cerebral inflammation, can you tell us more about those and where we can find someone to help?

A. HYPERBARIC OXYGEN HAS BENEFIT IN FIXING THE BRAIN. IF THERE ARE HYPOPERFUSION DEFECTS. HOW DO YOU REPAIR THE HYPOPERFUSION? MAYBE LDN, MAYBE NATURAL ANTICOAGULANTS TO DEAL WITH THE MICROCLOTS. WE DON'T KNOW. BUT THEORETICALLY SUCH TREATMENTS MAY BENEFIT AND DO 'NO HARM'.

Q. Is there any evidence of disturbance to Gut Microbiome and either a lack of available nutrients for the body or changed mood-Mental function?

A. THERE ARE STUDIES ON THE MICROBIOME. SEE MY SLIDE PRESENTATION.

Comment: Prof Lambert - an excellent research summary. I work in London as a Chinese TCM -Shiatsu doctor. I treated a few Long Covid patients with improvements on acupoints / meridians: Liver - (get more energy, less listless) Gall Bladder - (mental clarity) Triple Heater (Sanjian) - increase body heat, deeper breathing.

Lungs - clear up blocked lungs and improve breathing Spleen - improve blood quality and autoimmune system Bladder - unblock CNS Central Nervous System and get more sleep.

A. UNTIL WE GET THE 'MAGIC BULLETS' FROM TRADITIONAL MEDICINE, I THINK WE NEED PUBLICATIONS OR CASE STUDIES REPORTED FROM 'ALTERNATIVE MEDICINES' I PERSONALLY USE TCM AND ACUPUNCTURE FOR MY SINUS PROBLEMS, AND IT WORKS BETTER THAN MY SPECIALTY OF ALLOPATHIC MEDICINE. SO I WOULD ENCOURAGE PATIENTS TO TRY THESE OPTIONS.

Q. Any parasite testing done on people with Long Covid?

A. PARASITES ARE NOT THE PROBLEM. A LOWERED IMMUNE SYSTEM IS THE PROBLEM.

Q. Is there epigenome (gene expression and switching)?

A. THEORETICALLY POSSIBLE

Q. Would you put Ivabradine in the same league as beta blockers i.e., collateral damage? I have been on LDN 4.5 mg for 7 months and started ivabradine (script from cardiologist) 2 weeks ago 2.5mg for 1 month to 5mg for 5 months but may not be able to tolerate it due to low blood pressure. What is your opinion of ivabradine?

A. IT IS NOT THE MAGIC BULLET. BUT IF YOU NEED IT, IT IS A BETTER OPTION THAN BETA BLOCKERS.

Q. How can the mitochondria be repaired?

A. THE THINKING IS THIS IS DEFICIENCY OF GLUTATHIONE. SO REPLACE THE GLUTATHIONE. KIDS WITH MITOCHONDRIAL DISORDERS ARE GIVEN NAC 600MG BD. TO HELP CONTROL THE 'CRASHING' SO, WORTH A TRY AS THERE ARE SIMILARITIES WITH THE CRASHING SEEN WITH LONG COVID

Q. What is the expected outcome of repeated COVID19 infections in Long Covid patients? Should the government make more effort to reduce transmission?

A. IT'S NEVER GOOD. EACH COVID INFECTION HITS THE LYMPHOCYTES THAT ARE ALREADY DAMAGED. SO AVOID REPEATED COVID INFECTIONS.

Q. Is it possible that reinfections will lead to further deterioration (going from moderate to severe for example)? Or does this occur only as a result of PEM / attempting to push through?

A. A NEW INFECTION: CRASH. PUSHING TOO FAR: CRASH. I CALL IT AN IMMUNOLOGICAL CRASH. AND YOU GET REACTIVATION/EXACERBATION OF YOUR SYMPTOMS. IS IT THE IMMUNE SYSTEM, IS IT REACTIVEATION OF LATENT HERPES INFECTIONS. WE DON'T KNOW. IN THE MEANTIME, PACE DON'T PUSH.

Q. Is there any evidence of fungal changes in Long Covid patients - e.g., in the gut?

A. IN ACUTE COVID THERE IS EVIDENCE OF FUNGAL/MOULD INFECTIONS BEING SELECTED FOR. SO COVID CAUSES IMMUNOLOGICAL DAMAGE TO MAKE YOU MORE PRONE TO CATCHING THESE INFECTIONS. I HAVE NOT SEEN THIS WITH LONG COVID, BUT IT IS THEORETICALLY POSSIBLE. EITHER WAY, REPAIR THE IMMUNE SYSTEM. AND WE WILL NOT HAVE TO WORRY ABOUT VIRUSES, PARASITES, FUNGI.

Q. Or is a person likely to become more tolerant of reinfections over time?

A. THERE IS DAMAGE EACH TIME.

Q. Is anyone looking at neurotransmitters and chemical/electrical signalling changes after Covid?

A. I AM NOT AWARE. BUT I USE THE ANALOGY BRAIN DAMAGE/CONCUSSION. THERE MUST BE ELECTRICAL SIGNALLING CHANGES. SIMILAR PROCESS IN CHRONIC LYME/LONG COVID I THINK. BUT THERE HAS BEEEN NO SUPPORT FOR STUDIES TO INVESTIGATE CHRONIC LYME, ME/CFS. EVERY RESEARCHER WHO SUBMITS AN APPLICATION TO STUDY THIS, THE REVIEWERS REJECT THE APPLICATION AND FUNDING FOR SAME. THE REVIEWERS OF THESE APPLICATIONS HAVE CATEGORISED ALL OF THESE CONDITIONS AS 'NON-EXISTENT' OR PSYCHOLOGICAL. IT IS SHAMEFUL. WE SHOULD BE ENCOURAGING NEW SCIENCE, NOT SUPPRESSING IT. BUT IT IS BEING SUPPRESSED.

Q. How can you help with Coxsackie reactivation post Covid?

A. REPAIR THE IMMUNE SYSTEM. CHRONIC VIRUSES CANNOT BE ELIMINATED. JUST CONTROLLED.

Comment: POTS may also have CIRS underlying & do well with certain binders, YES.

A. POTS JUST MEANS YOUR BLOOD PRESSURE AND YOUR HEART RATE ARE LABILE. TOO FAST AND TOO SLOW, TOO HIGH, AND TOO LOW. WHAT UNDERLIES THIS CONDITION, AND HOW DO YOU GET IT BETTER?

Q. I heard elsewhere that LC is more prevalent in overcrowded and polluted areas?

A. YES. THOSE WHO ARE IMMUNOLOGICALLY DISADVANTAGED ARE MORE AT RISK

Q. Have you got Traditional Chinese Medicine in your Ireland medical work & research as a potential Long Covid countermeasure?

A. YES. BUT IT WOULD BE GOOD TO GET SOME PUBLICATIONS FROM THE TCM PRACTITIONERS ON HOW THEIR TREATMENTS ARE WORKING.

Q. Can vagus nerve stimulation devices help?

A. NOT PROVEN FOR LC. BUT IS BEING USED FOR NEUROPSYCH CONDITIONS AND STUDIES TO PROVE THEIR BENEFIT. PART OF THE PROBLEM WITH LC IS NEUROPSYCH. SO IT IS A NO-BRAINER. TRY IT. ALSO SEEMS TO HELP WITH GUT/INTESTINAL DYSAUTONOMIA.

Q. Where do you find out more about PACING?

A. <u>https://longcovid.physio/pacing</u> IF ANYONE TELLS YOU TO DO GRADED EXERCISE, TELL THEM TO CHECK THE SCIENCE. PUBMED.CENTRAL.

Comment: There are no disability benefits (?) in England for Long Covid?

Response: THERE SHOULD BE DISABILITY BENEFITS, BOTH IN UK AND IRELAND. PEOPLE ARE STILL BEING PUT INTO THE PSYCHIATRIC BASKET. AND DENIED THE PATHOPHYSIOLOGY. CHECK THE PET SCANS OF THE BRAIN.

Q. Is there any hope? I have a 15-year-old. Previously fit and well, COVID September 2021....so depressed, dropping GCSE'S. Reduced school attendance and no social life. Life for her is hopeless. Throwing supplements and amitriptyline at it, but other than pacing she has nothing.

A. I HAVE PROVIDED A LIST OF SUPPLEMENTS THAT MAY HELP, NOTHING IS PROVEN TO HELP. MULTIVIT WITH COENZYME Q10, SUBLYME ESSENTIAL CAPSULES OR NAC, LOW DOSE NALTREXONE. CONSIDER HBOT, IF SLEEP DISTURBANCE CONSIDER MELATONIN

Q. Has anyone else developed erythromelalgia as a consequence of Covid (it is burning red hot feet which turn red and hot to touch, with prolonged standing or walking/exercise)?

A. I HAVE SEEN THIS. IS THIS A MICROCLOT PHENOMENOM, PERIPHERAL NEUROPATHY, ACTIVATION/ RELAPSE OF BARTONELLA.... ALL POSSIBILITIES.

Q. I have had Long Covid for 3 years and suffered numerous symptoms, most of which you mention. I have undergone numerous tests and therapies. I currently continue to suffer with a heavy head which can be very painful and sore throat painful tongue and slurred speech. Any suggestions as to how I can get better please?

A. WOULD SUGGEST LDN AND SERIES OF SUPPLEMENTS. ALSO, YOU SHOULD BE REFERRED TO OCCUPATIONAL NEURO REHAB SPECIALIST TO RETRAIN THE BRAIN.

Q. Is there any evidence of the Paleo-Keto diet reducing symptoms?

A. THE MICROBIOME IS YOUR IMMUNE SYSTEM. MAKES SENSE TO REPAIR IT TO SEE IF THERE IS IMPROVEMENT IN CENTRAL SYMPTOMS. YOUR GUT IS 90% OF YOUR IMMUNE SYSTEM. SO, REPAIR THE IMMUNE SYSTEM IN ALL WAYS POSSIBLE.

Comment: Dealing with chronic Lyme for decades. now after COVID last October. Long Covid! Brought huge flare and ALL my symptoms back. worse... pains jabbing me awake all night long... tinnitus. histamine issues... mast cell... etc... and my local docs still offering no help.

Response: WOULD ADVISE GOING BACK ON THE ANTI-BACTERIAL TREATMENT THAT WORKED BEFORE. AS YOU LIKELY HAVE RELAPSING BACTERIAL INFECTION. AND GO BACK ON ALL THE SUPPLEMENTS TO REPAIR THE INFLAMMATION AND THE IMMUNE DYSREGULATION.

Comment: I've had really good results with clients that I have put on a low-histamine, antiinflammatory, high-polyphenol diet. I hope to publish a paper soon.

Response: GOOD LUCK IN GETTING PUBLISHED. SO MANY GOOD WORKS ARE REJECTED. EITHER WAY, THE IMMUNE SYSTEM IS DAMAGED, THE LYMPHOCYTES ARE DAMAGED, REPAIRING THIS DAMAGE IS PART OF THE SOLUTION.

Q. What exactly is neuro rehab?

A. GET IN A CAR CRASH AND HAVE A CONCUSSION. BE A RUGBY PLAYER AND GET HIT TO THE HEAD, AND BRAIN INJURY. THERE ARE A WHOLE RANGE OF SPECIALISTS IN IRELAND WHO MANAGE THESE CONDITIONS. REHABILITATION SPECIALIST CONSULTANTS, NEUROPHYSIOTHERAPISTS AND OCCUPATIONAL THERAPISTS. THEY NOW NEED TO APPLY THEIR SKILLS TO MANAGING THE BRAIN COMPLICATION OF LONG COVID. THAT IS NEURO REHAB.

Comment: My brain fog lifted either after using CBD oil regularly or lactoferrin or good Omega 3, taking all at the same time!

Response: NO MAGIC CURES. BUT THESE ARE SAFE OPTIONS.

Comment: Having recovered from chronic Lyme (Thank you Dr Lambert! A) I don't want to risk COVID and will continue to mask in indoor shared spaces. It's interesting seeing how many similarities there are between Long Covid and Lyme. Not just with symptoms, but with how patients are dismissed and ignored by doctors who do not understand.

Response: I SHOWED, IN MY PRESENTATION/POWERPOINT, THE PET BRAIN SCANS THAT SHOW THE SIMILAR ABNORMALITIES WITH CHRONIC LYME AND LONG COVID.

Comment: Biomagnetic Pair Therapy has been a wonderful therapy at rehabilitating from Long Covid.

Response: I DON'T KNOW HOW BIOMAGNETICS WORKS, BUT PATIENTS REPORT IT HELPS THEM IN MANY CASES, AND AT LEAST IT DOES NO HARM.

Comment: Acupuncture may help as well on a neurological level

Response: THERE IS CLEAR EVIDENCE IN THE SCIENTIFIC PUBLICATIONS THAT ACUPUNCTURE CAN HELP.

Comment: I think I have mitochondrial dysfunction and started NAC 600mg in January. GI reactions so giving a break for a week and starting again on 300mg.

Response: MOST PEOPLE CAN TOLERATE. OPTIONS INCLUDE GOING TO GLUTATHIONE OR LIPOSOMAL GLUTATHIONE. NAC IS THE CHEAPER ALTERNATIVE, BUT THE END RESULT IS REPAIRING THE MITOCHONDRIA.

Q. Any comments on studies made on Heart Rate Variability being unstable in Long Covid patients, possibly causing fatigue?

A. IT'S THE VAGUS NERVE AND THE SYMPATHETIC/PARASYMPATHETIC SYSTEM IMBALANCE CAUSING THIS 'INSTABILITY'. SO, REPAIR IT IN MORE NATURAL WAYS, REPAIR THE VAGUS NERVE, EXERCISE TO RECONDITION THE S/PS SYSTEM.

Comment: My personal experience with ME/CFS is that exercise/physical activity can be accessible and beneficial for SOME people. This is NOT based on a deconditioning model, but rather that exercise has great benefits for everyone. It requires personal experimentation, lots of rest, acceptance of some payback, use of data (RHR/HRV), nutritional support. More accessible for people previously fit.

Response: PACE DON'T PUSH. AS A RULE, THIS IS THE MANTRA THAT WORKS.

Comment: I have found this very much the case, with disastrous consequences, overdoing has landed me and many other patients utterly bedbound'

Response: CRASH CRASH CRASH. PACE PACE PACE.

Comment: For ageusia try acupuncture, I got Covid March 2020 went to Chinese nurse she used needles in my sinus and after 27 months I walked out and taste again.

Response: YES. THERE IS SCIENTIFIC EVIDENCE OF THE BENEFITS OF ACUPUNCTURE.

Comment: FLCCC also uses Ivermectin for Long Covid because in part the anti-inflammatory impact on brain, I think.

Response: NOT SURE OF THE ROLE OF IVERMECTIN IN LONG COVID. I THINK THE STUDIES IN THE ACUTE PHASE OF COVID SHOW IT COULD BE PART OF THE SOLUTION OF TREATMENTS TO SUPPORT SUCH PATIENTS.

Q. Any particular treatment to help Covid toes? Is this a sign of vascular damage? Actual infection was mildish...

A. THE COVID TOE. I THINK IT IS MICROVASCULAR INFLAMMATION. I HAVE USED NATTOKINASE, LOW DOSE ASPIRIN, AS I THINK IT MIGHT BE LACK OF BLOOD FLOW. FOR SYMPTOMATIC RELIEF HAVE TRIED COLCHICINE WITH VARIABLE SUCCESS.

Q. You have a clinic in EDINBURGH now? I saw you 3 years ago in Dublin... too far and expensive to go to now from Scotland! But I could manage EDINBURGH!

A. I RUN MONTHLY CLINICS IN EDINBURGH. I AM SCOTTISH AND HAVE RESIDENCE IN KINGHORN. IF YOU NEED APPT <u>ADMIN@IDDOCTOR.EU</u>

Comment: I can't even go for a walk now without crashing and previously was a kettlebell athlete and S&C Pilates powerlifting etc. Did a half marathon in 2018. I don't even recognise myself.

Response: SORRY ABOUT THAT. I HAVE OUTLINED MY SUGGESTED PLAN FOR RECOVERY AND AVOIDING CRASHING.

Comment: Same Siobhan, I was training 3 times per week, running, open water swimming, cycling and yoga. now nothing other than walking and light yoga.

Response: HOPEFULLY THE DAMAGE IS REPAIRABLE. BRAIN DAMAGE, IMMUNE DYSFUNCTION.

Q. Is there an agreed scale for stratifying Long Covid patients for better direction of treatment pathways?

A. NOT AT PRESENT.

Comment: For what it's worth - I have the autonomic dysfunction LC variant - gentle yoga seems to help. Especially the exercises that " send " blood to the head (bending, being upside down).

Response: APPROVE

Q. In terms of prevention, are doctors in the Long Covid community advocating for wider Paxlovid access?

A. STILL EARLY DAYS. PAXLOVID IS AN ANTIVIRAL TARGETTING ACTIVE VIRUS REPLICATION.

Q. Are fungal infections common after a Covid infection?

A. NOT WELL RECOGNISED. ONLY IN THE ACUTE COVID INFECTION.

Comment: Doctors should be fighting for/advocating for their patients more, I and challenging the regulators, rather than protecting their own careers.

Response: SORRY BUT YOU ARE RIGHT. MOST OF MY COLLEAGUES ARE TRYING TO CONVINCE PATIENTS GETTING BETTER NOT TO TAKE LDN. WHY?

Q. I suspect environmental pollution is a major contributing risk factor (e.g. Glyphosate, toxic metals); do you consider this to be?

A. YOUR IMMUNE SYSTEM CONTROLS COVID AND LONG COVID. ANY INSULTS TO YOUR IMMUNE SYSTEM CAN ADD TO THE PROBLEM.

Q. Is there an opportunity to explore urine metabolomics after exercise in Long Covid patients? For example, as per the Glass (2023) recent study highlighting possible lack of adaptation in ME/CFS patients after exercise challenge.

A. STUDIES NEED TO BE PUBLISHED. TO SUPPORT.

Comment: I would like to say that my post Covid Dysautonomia is not hyperadrenergic, but small fibre neuropathy so breathing will not help.

Response: THERE IS AN ELEMENT OF SMALL FIBRE DAMAGE, YES, I AGREE. BUT IT IS NOT ALL ONE OR THE OTHER. SOME OF IT IS CENTRAL BRAIN SIGNALLING.

Comment: Hyperadrenergic POTS raises BP

Response: YES, I WOULD AGREE.

Q. Histamine issues and mast cell common after Covid?

A. I WOULD SAY 10% OF LONG COVID PATIENTS HAVE MAST CELL/HISTAMINE PROBLEMS. DAMAGED LYMPHOCYTES I WOULD SAY.

Comment: I'm currently doing the IMMA course, find Mycotherapy so helpful for Long Covid and EBV clients

Response: EVERYONE CLINGS TO THE NEXT 'HOPE' FOR A CURE. SHOW ME THE DATA MYCOTHERAPY ADVOCATES. I DON'T SEE THE DATA, DON'T SEE THE SCIENTIFIC RATIONALE. BUT WILLING TO REVIEW THE DATA TO RECONSIDER. **Q.** One or two patients have had success with tocilizumab - any chance this will be studied more widely?

A. I HAVE USED TOC IN THE SETTING OF ACUTE INFECTION. BLOCKS IL6, ONE OF THE CYTOKINES OVER EXPRESSED IN COVID. NO STUDIES IN LC THAT I AM AWARE OF.

Q. What might a neuro-rehabilitation programme look like? Are there existing specialisms that could help on this front - geriatric specialists, dementia, Parkinson's specialists?

A. CONCUSSION, CLOSED HEAD INJURY THAT IS THE MODEL. LOTS OF EXPERIENCE WITH THESE CONDITIONS IN IRELAND. LOOK AT RUGBY AND THOSE WITH CONCUSSION. ADAPT THE SAME NEUROTHERAPIES TO LONG COVID CNS DAMAGE.

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