

THE INIM



• WINTER 2021 •

NOVA SOUTHEASTERN
UNIVERSITY



INIM COVID-19 Update

The Institute for Neuro-Immune Medicine is taking actions to prevent and slow the spread of COVID-19, while continuing to offer care and resources to our community. We want to thank each and every one of you for your patience and understanding during this uncertain time.

We have begun seeing patients at our Davie and Kendall clinics on a case by case basis and will continue to conduct Telehealth appointments.

Continue to visit our website and check our social media channels for ongoing updates.

If making a campus visit:

BE A SMART SHARK.

MAINTAIN PHYSICAL DISTANCE. <i>Handshakes and hugs aren't a good idea, but a wave and a "Fins Up!" are!</i>	USE A FACE COVERING. <i>Cover your mouth and nose and avoid touching your face.</i>	WASH YOUR HANDS, PLEASE. <i>Spend at least 20 seconds and use plenty of soap and water.</i>
DON'T FEEL WELL? STAY HOME. <i>Monitor your symptoms and call your doctor early on.</i>	KEEP IT CLEAN. <i>Clean and disinfect all surfaces and objects you frequently touch.</i>	STAY INFORMED. <i>Visit nova.edu/coronavirus and cdc.gov for updates and to keep yourself safe.</i>

NSU Florida

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- WEBINAR RECAP -

MANAGING THE SYNDROME SOUP: POTS, EDS, MCAS & ME/CFS

- JOINT PROVIDER DYSAUTONOMIA INTERNATIONAL

CME VIRTUAL WORKSHOP MANAGING THE SYNDROME SOUP: POTS, EDS, MCAS & ME/CFS

Saturday, December 5, 2020

DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



ADVANCEMENT

Dr. Kiran C. Patel College
of Osteopathic Medicine
NOVA SOUTHEASTERN UNIVERSITY

Institute for
Neuro-Immune Medicine
NOVA SOUTHEASTERN UNIVERSITY

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SPEAKERS

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Postdoctoral Fellow
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Peter Rowe, MD

Director, Children's Center
Chronic Fatigue Clinic
Professor of Pediatrics
Johns Hopkins University

Lauren Stiles, JD

President & Co-Founder
Dysautonomia International
Research Assistant Professor of Neurology
Stony Brook University School of Medicine

The Institute for Neuro-Immune Medicine and Dysautonomia International held a virtual CME workshop on Saturday, December 5, 2020 to educate clinicians about what they can do to help patients manage the "syndrome soup."

This Continuing Medical Education event was intended for a clinician audience, but patients and caregivers were welcome to attend too.

Click on the image above, or follow this link: <https://www.nova.edu/nim/events.html> to view the recording.

Please note: only registered participants can receive access to the recordings.

FACULTY/STAFF ANNOUNCEMENTS



The INIM's E.M. Papper Laboratory of Clinical Immunology's Assistant Professor, Lubov Nathanson, PhD, has been appointed to the position of Endowed Professor for Dr. Kiran C. Patel College of Osteopathic Medicine (KPCOM). This endowment was made possible with a generous grant by Mr. Robert Schemel.

The first recipient of this award was Mary Ann Fletcher, PhD, who made great contributions in clinical laboratory medicine. Dr. Nathanson is a well-respected and prolific researcher at the Institute for Neuro-Immune Medicine, whose contributions to KPCOM are invaluable.

We are excited to welcome Nicole Cook, PhD, MPA! Dr. Cook will be working on our newest study with the Center for Disease Control, COVID-19: Understanding the Post-Viral Phase, Also known as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): A Sequelae of COVID-19 Infection.

Dr. Cook, is currently an Associate Professor of Public Health at Nova Southeastern University. Her funding includes serving as the Co-PI under Dr. Klimas on this COVID-19 longitudinal “long hauler” study. This epidemiologic study surveys a community-based population in sufficient numbers to estimate the risk of long-term ME/CFS-like symptoms following infection of COVID-19.



To Vaccinate or Not - with ME/CFS

By Nancy Klimas, MD, Director, Institute for Neuro-Immune Medicine



Veterans with concerns related to Gulf War illness have a lot in common with ME/CFS patients, so my advice to them is the same. See the article below.

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-19.

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 can tolerate. (Benadryl is one of the strongest, Zyrtec is another good choice). There are many mast cell stabilizers; watch Dr. Maitland's excellent lecture from our recent CME Workshop: Managing the Syndrome Soup: POTS, EDS, MCAS & ME/CFS, if you want to know more: <http://bit.ly/NovaDysCME>

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, S-AMe, 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-19 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-19 precautions very seriously). If 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 recommended 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. Although they came to the 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). Vaccination does not exclude strict social distancing guidelines and mask wearing 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 must be moved by the photos of health care professionals lining up to receive their vaccine. Is there a risk? Yes. There is certainly more of 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. More than 330,000 Americans have died. 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 CDC has issued guidance on COVID-19 vaccines and severe allergic reactions. According to the CDC, if you have a severe allergic reaction after getting the first shot, you should not get the second shot. Additionally, the CDC notes patients who experience a severe allergic reaction may be referred by their doctor to a specialist in allergies and immunology to provide more care or advice.
- 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 Authorization 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.
- If you have questions related to the risk of an allergic reaction to either of the mRNA COVID-19 vaccines, contact your local board-certified allergist/immunologist.

Reference: <https://acaai.org/news/american-college-allergy-asthma-and-immunology-updates-guidance-risk-allergic-reactions-mrna>

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.

To learn more, follow this 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.

INIM'S HELPING HAND



Last month, we launched INIM's Helping Hand to help provide INIM's patients with the care they require on their road to wellness.

As the premiere clinical and research-based institute, the INIM has catapulted to the forefront of patient care for ME/CFS and other complex illnesses. It is because of this recognition that the INIM receives numerous calls a day from individuals hoping to be seen in our clinic. Unfortunately, many of these individuals are unable to afford the patient care they deserve.

Please consider giving the gift of healthcare to a patient in need and make a true difference in someone's life.



[DONATE TODAY!](#)

GULF WAR ILLNESS RESEARCH PARTICIPATION DURING COVID-19



Gulf War Illness Research Participation During COVID-...



"We need to keep the momentum going..." This call-to-action coming from Nancy Klimas, M.D., Director of the Institute for Neuro-Immune Medicine and Director of Clinical Immunology Research at the Veterans Affairs Medical Center, as fears about the coronavirus is keeping people from wanting to participate in research.

Now more than ever, it is critical to participate in Gulf War illness research. We are following COVID-19 protocols to ensure participant's safety and to maintain research momentum.

Sign up for emails to stay updated with the INIM on new research, institute updates, upcoming events, and much more!



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