From Dr. Nancy Klimas

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 out 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, SAMe, quercetin, and natural sources of theophylline like green and black teas.

If you have been diagnosed with mast cell activation syndrome, it would make sense that your risk of an immediate reaction to any vaccine should be higher, though the data on the risk to people with mast cell activation syndrome or prior vaccine allergic reactions is not yet known with the COVID-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 Authorisation by the US Food and Drug Administration should be undertaken by the individual, along with their physician or other provider administering the vaccine using their professional judgment balancing the benefits and risks associated with taking the vaccine.

\*            People with common allergies to medications, foods, inhalants, insects and latex are no more likely than the general public to have an allergic reaction to the mRNA COVID-19 vaccines. Those patients should be informed of the benefits of the vaccine versus its risks.

\*            The mRNA COVID-19 vaccines are not live vaccines and can be administered to immunocompromised patients. Physicians and other providers should inform such immunocompromised patients of the possibility of a diminished immune response to the vaccines.

\*            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.

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