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Notes on the H1N1 vaccine for people with ME/CFS Update, December 3, 2009

Disclaimer: The information below is provided for you to consider with your health care provider. It is provided for information purposes only. As a resource group, the function of our organization is to provide you with current information on ME/CFS. As we are not medical or legal professionals, we accept no responsibility for how this information might be applied. We urge you to discuss all aspects of your needs with your doctors before making any decisions.

In our Fall 2009 newsletter, we provided you with an article about the H1N1 virus and ways of preventing transmission. At that time, little was known about the availability of the vaccines for H1N1 and we referred those with questions about vaccines to Dr. Basted's article about seasonal flu vaccines from our Fall 2008 newsletter and to several government websites. We've included both of these earlier articles at the end of this one, for your information.

At this time, in most areas of Ontario, H1N1 vaccines are being made available to all citizens who want one and we now have more information on the types of vaccines available, any early reports of adverse drug reactions to the vaccines, and information on treatments for those infected. We've received close to 100 calls and emails about H1N1 and at this time print information is likely more helpful to those deciding and less stressful to our Info Line staff and volunteers. So we wanted to provide you with an update on H1N1 vaccines to provide you with the information you need to make an informed choice.

People with ME/CFS and Flu Vaccines

Many patients with M.E. have reported adverse reactions to seasonal flu vaccinations, but not all. Dr. Alison Basted has previously written about this phenomenon, as have many physicians worldwide. (See the MEAO newsletter for Fall 2008, attached.) If you have taken flu shots in the past without problems, there is no reason to believe you will react badly to the H1N1 vaccine that follows the same method, known as the unadjuvanted vaccine. However, if you have felt ill for days or weeks after a seasonal flu vaccination this may occur with the H1N1 vaccine as well. **And anyone with an allergy to eggs or a proven allergy to previous vaccines (anaphylaxis) should always speak to their doctor about alternatives to vaccinations.**

It is reported that people with M.E. can feel ill immediately after having a seasonal flu vaccination, with the symptoms lasting for days or weeks. Some people feel the vaccinations trigger a relapse of their symptoms. Others do not report such problems. It is certainly true that many people with ME/CFS also report that contracting a flu – like H1N1 – also can trigger their M.E. So the decision whether to have a vaccine or not is not simple.

Dr. Lapp has reported that some people with M.E. do not always benefit from vaccinations because they may not "sero-convert", or build up the appropriate antibodies after taking vaccinations. Patients may be experiencing physical setbacks to their M.E. without even

developing the protective antibodies from the vaccine (<http://www.drlapp.net/resources.htm>). Flu vaccines are not 100% effective. Some people do not develop full immunity after their vaccine, but if they do become infected, the symptoms from that flu are usually milder because of the vaccine.

How Serious is H1N1?

H1N1 is a very serious virus and is causing illness and death in young people, as well as those with other medical conditions so even those with M.E. who might not normally choose a seasonal flu vaccine may wish to make a different decision this year regarding H1N1. As of December 1, 2009, there have been 309 reported deaths from H1N1 in Canada (from FightFlu.ca) and these numbers will grow. Reports about deaths from other seasonal flu often estimate that 2,000 people or so will die each year from complications caused by the flu, meaning that most have other illnesses and the flu contributed to their death. This can happen with H1N1 but H1N1 is also serious enough that it can cause death, on its own, in otherwise healthy young people.

Only you can personally weigh the consequences of taking the vaccination (it may trigger your M.E.) versus the possible dangers of not taking the vaccination – getting H1N1 and also perhaps passing it on to others.

“I think I have H1N1 or a family member may have it”:

If you have symptoms, or someone else in your family has symptoms or diagnosed H1N1 – your best step is to see your family physician. If you are ill, you should limit your exposure to others and go to a doctor or clinic that can diagnose H1N1 and not to a vaccination clinic. Wear a mask when you have to leave the home for medical treatment and follow all of our advice from our H1N1 Fact Sheet found on pages 7-9. If you have already contracted H1N1, a vaccine will not help you at this time.

If you become ill with H1N1, please see your physician as soon as possible for an examination. While some otherwise-healthy people who contract H1N1 may be told to stay home and only go to a doctor if they become very ill, people with ME/CFS should consult their doctor at the outset and certainly if they develop any of the signs that H1N1 is serious for them:

- high fever or fever for more than three days
- shortness of breath
- difficulty breathing (chest tightness, wheezing)

If these symptoms develop, consult with a doctor or hospital immediately. These symptoms can indicate pneumonia or another secondary infection or they could mean your system is having difficulty fighting off the H1N1 virus.

What if I have Other Serious Health Problems?

Because H1N1 is a virus that primarily affects the lungs and respiratory system, if you have any breathing/respiratory problems H1N1 could be more difficult for you. If you have:

- asthma;
- a history of repeated bouts of pneumonia;
- chronic bronchitis; or,
- COPD (Chronic Obstructive Pulmonary Disease)

it is important for you to get assistance with your symptoms as soon as possible.

Other illnesses or conditions that could make H1N1 more difficult to fight include:

- heart disease
- diabetes
- diseases of the kidneys or liver
- any neurological disease that can affect your breathing
- compromised immune systems due to illness or treatments for cancer or leukemia
- pregnancy

Medical Treatments for H1N1:

Most people, including those with ME/CFS, will experience symptoms for a week to 10 days that will be no more serious than an annual flu. Most people will recover with complete rest, fluids, fever/pain relievers, if necessary.

Antiviral drugs can be effective in reducing the virus. They can:

- reduce the severity of the symptoms you have;
- the length of the illness;
- the chance of developing serious complications.

Some doctors will recommend antiviral drugs for patients with ME/CFS. They are usually prescribed for people who develop significant symptoms right away, or for those with the other serious health problems, as mentioned above. Some patients will choose to take antivirals immediately on diagnosis “just to be sure”. These antiviral drugs must be taken shortly after you become sick – usually in the first 24 to 48 hours.

If an antiviral drug is recommended for you, ME/CFS physicians are recommending that you can take Tamiflu© (oseltamivir) right after becoming ill with H1N1. There are no early indications that Tamiflu© has posed problems for people with ME/CFS but no research has been collected about H1N1 illness or Tamiflu© usage for people with ME/CFS so we cannot be certain people with ME/CFS will take antivirals without problems.

I Don't Think I've Had H1N1 and I'm Trying to Decide Whether to Vaccinate:

Most people with M.E. probably fall into this category.

Vaccines contain antigens that trick the immune system into thinking it is being attacked by the H1N1 virus so it produces antibodies and prevents infection from the real H1N1 virus. It takes about a week for immunity to develop after vaccination.

There are two types of H1N1 vaccines:

1) Adjuvanted: An adjuvant is a substance added to bolster, or assist, the antigens in the vaccine. The vaccine Canada is using is made by GlaxoSmithKline and is called Arepanrix. This vaccine uses an adjuvant called AS03, which contains squalene (shark liver oil), DL-alpha-tocopherol (vitamin E) and polysorbate 80 (an emulsifier also used in some foods, creams, etc.).

As of November 14, 2009, the Public Health Agency of Canada has reported adverse events (fever or flu-like symptoms, arthritis-type symptoms after a vaccination) in 21.38 of every 100,000 vaccinations but serious adverse events (allergic reaction, hospitalization, death) after only 1.8 of every 100,000 vaccinations. The seasonal flu vaccine usually results in serious adverse events for 1 out of every 100,000 vaccinations.

<http://www.phac-aspc.gc.ca/alert-alerte/h1n1/vacc/addeve-eng.php>

Though the number of serious or severe adverse drug reactions is described as small, ALMOST ALL SERIOUS OR SEVERE REACTIONS OCCURRED WITH THE VACCINES WITH THE ADJUVANTS. It seems that one batch in particular may have caused more reactions than others, but otherwise it is not known why the vaccine with the adjuvants caused more adverse events.

Squalene may lead to allergic reactions and there are claims that that the squalene used in the anthrax vaccine may have led to Gulf War syndrome – but the evidence is not accepted by everyone. Polysorbate 80, when injected, as in vaccines, may lead to fainting and anaphylaxis (severe allergy) in some people, so that may be another reason. It may be many months before the Public Health Agency of Canada has all the data on the vaccines

2) Unadjuvanted: Some people have therefore asked us if they should request "unadjuvanted" vaccine (the one without the added drugs to boost the vaccine). This vaccine is called Panvax and is made by CSL Australia. Many doctors are now recommending that if people with ME/CFS decide to take an H1N1 vaccine, they should consider the unadjuvanted vaccine:

- People with ME/CFS generally respond better when fewer chemicals or boosters are used;
- The recent Public Health Agency of Canada statistics showing more adverse drug reactions to the adjuvanted vaccine provides some evidence that the unadjuvanted vaccine is possibly safer for people with ME/CFS.

However you should also know that the unadjuvanted vaccine has more of the preservative Thimerosal (mercury) at 50 micrograms compared to 5 micrograms of the adjuvanted variety. So while you are getting fewer chemicals in using the unadjuvanted vaccine, you are getting a

higher dose of Thimerosal. Thimerosal is known to cause allergic reaction in some people and if you have a known sensitivity to Thimerosal this vaccine will have higher doses than the usual seasonal flu vaccine and is not for you.

Some researchers believe that patients can be sensitive to Thimerosal (mercury) without showing the full allergic reaction; they may feel ill after flu and travel vaccinations. Thimerosal may be one of the reasons why people with ME/CFS get sick after vaccinations. If this describes you, talk with your doctor about trying to get vaccinations in the future without Thimerosal. Unfortunately all the H1N1 vaccines have some Thimerosal but the Unadjuvanted has 10 times the trace amount of Thimerosal over the Adjuvanted one.

WE WISH WE COULD PROVIDE YOU WITH A SIMPLE STRAIGHTFORWARD DIRECTIVE TO VACCINATE OR NOT VACCINATE, BUT THIS DECISION IS TOO COMPLEX AND YOU MUST MAKE YOUR OWN INFORMED CHOICE.

I've Decided to Vaccinate. Where do I go?

The availability of the vaccines has changed almost weekly so the following information is based on guidelines from Toronto Public Health and other regions as of December 3, 2009

Adjuvanted Vaccines: Up until about December 13, 2009 you will be able to go to any of the mass vaccination clinics set up in your area. Contact your local Public Health Department to find a clinic near you.

Unadjuvanted Vaccines: Guidance from Public Health has varied widely on this and we have had many complaints from MEAO members about this. Currently YOU CANNOT GET THE UNADJUVANTED VACCINE IN MOST MASS VACCINATION CLINICS UNLESS YOU ARE PREGNANT. Call before you go to your clinic. Durham Region clinics will give the unadjuvanted vaccine but Toronto clinics will not.

It is best if you call your family physician or Community Health Clinic and tell them you want them to order the unadjuvanted vaccine for you. Public Health is making it available in batches as small as 10 vials, or in larger batches, for any family physician for any of their patients who request it. The doctor can call the Vaccine Ordering Line from their local public health department. In Toronto it is 416.338.2029. Delivery may take a few days to a week.

We have been told that many doctors and family practice clinics are refusing to vaccinate anyone, sending them all to the mass clinics. The MEAO has written a letter of concern to Toronto Public Health about the confusion over vaccinations and its effect on our community. They have advised us that every person with ME/CFS who wants a vaccine has the right to have their doctor order the unadjuvanted vaccine and give it to them. The mass Public Health Clinics are about to close for the season so doctors must begin to vaccinate their patients, as they would for any flu any other year.

Can I Split My Dose / What About the Regular Seasonal Flu Vaccine?

Splitting the Dose:

If you take the vaccine, you may be considering asking the doctor to split the dose so you don't have to take it all at once. Some people with M.E. have used this strategy for many kinds of vaccinations in the past and they report that they tolerate the vaccinations better this way. With the H1N1 vaccine, children under age 10 are allowed to split the dose into two, taken three weeks apart, because of their developing immune systems. As an adult with M.E., you may wish to ask to have the dose split in the same way. Some ME/CFS doctors have suggested splitting your vaccine into 3 or 4 doses, however Public Health has informed us that because the unadjuvanted vaccine requires a special order this may not be possible and splitting your dose into two, taken from one to three weeks apart may be the best you can achieve.

Remember that it takes at least one week after you have finished your full dosage before you have immunity. Until then, you can still develop H1N1.

What About Seasonal Flu Vaccine?

As we have shared with you in previous years (see below) seasonal flu vaccine shares many of the same drawbacks as H1N1 vaccine for people with ME/CFS. If you decide to also take a seasonal flu vaccine, the general recommendation is to take the H1N1 vaccine first and the seasonal flu second. While the Public Health Agency of Canada, citing U.S. research, states that people can take H1N1 vaccines and seasonal flu vaccines on the same day provided each vaccine is given into different arms, ME/CFS researchers believe the two shots together may overload the immune systems of people with ME/CFS and the vaccines should be taken a few weeks apart, to allow the body to develop a response to each vaccine separately.

The other benefit of waiting at least a week is to see if you can tolerate the vaccination process. If you have a serious reaction to the first vaccine you can discuss your options with your doctor about any further vaccines.

For More Information:

This is all the information on H1N1 the MEAO will be able to provide from this point forward. We hope you find these fact sheets helpful in making your decision.

For more information on H1N1 and vaccinations, you can go to the Public Health Agency of Canada Website: http://www.phac-aspc.gc.ca/alert-alerte/h1n1/vaccine_vaccin-eng.php

Government of Ontario: <http://www.health.gov.on.ca/en/ccom/flu/>

or the Toronto Public Health Website: <http://www.toronto.ca/health/cdc/h1n1/>

These are just a few notes offered to our members to discuss with their doctors. Please do not make any serious decisions regarding your health without discussing it with a qualified medical practitioner first.



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The following article is from the MEAO's quarterly newsletter Reaching Out and was presented in our Fall 2009 issue. If you are concerned about a seasonal flu vaccination or a H1N1 vaccination, please discuss the issue with your doctor after reading this, or any other material on vaccines. As a resource organization, our role is to provide you with current information on ME/CFS. As we are not medical professionals, we accept no responsibility for how this information might be applied. We urge you to discuss all aspects of your health with your attending physician.

YOU AND THE SWINE FLU – H1N1

Written by Theresa Dobko, MEAO Provincial Coordinator, from government and medical sources

What is H1N1 flu virus?

The H1N1 flu virus is a serious respiratory disease that can spread from person-to-person. This fall, it is expected to increase as we return to work and school.

How does H1N1 flu virus spread?

Flu viruses are spread mainly from person to person through the droplets released from coughing or sneezing. Sometimes people become infected by touching objects contaminated with H1N1 and then touching their mouth or nose.

- H1N1 can stay on your hands for 5 minutes if not washed correctly
- On fabric for 10 minutes
- On surfaces for 2 days if not disinfected

What are the symptoms of H1N1?

The symptoms of H1N1 flu virus are similar to the symptoms of other seasonal flus: chills, cough, sore throat, fatigue body aches or headaches. Most, but not all, people will get a fever. Some children and adults have diarrhea and vomiting. H1N1 can lead to pneumonia and other serious illnesses, including death.

How does my having ME/CFS affect getting H1N1?

Like other flus, H1N1 can be worse for those with another underlying medical condition. People with ME may have compromised immune systems which could make the virus harder to fight.

What should I do if I get sick?

If you become ill with the symptoms listed above, contact your doctor immediately, or call TeleHealth 1.866.797.0000, if your doctor is not available. They will help you determine if you need to be seen for treatment. Make sure you tell any health care provider you see that you have ME/CFS and that you may be at more risk for complications.

How long is someone infectious?

Someone with H1N1 may be infectious for 24 hours before the first symptom appears and for 7 days after becoming sick. Young children may be contagious for longer. That is why it is recommended that anyone with H1N1, or anyone exposed to H1N1, should stay home for 10 days, or until medically cleared.

Can I protect myself from H1N1?

For people with ME/CFS, avoid anyone who is ill, if you can, and consider avoiding busy public places during an outbreak. The following advice is for all Canadians:

- Wash your hands often with soap and warm water, for at least 20 seconds. Wash after each time you cough/sneeze and when coming home.
- 60% -90% alcohol-based hand rub is effective when soap/water are not available. Use unscented product without other additives if you have ME. *Microsan Encore* is one brand.
- Sneeze and cough into a tissue or your sleeve so the virus droplets can't spread. Throw tissues into the trash right after use.
- Most people should not wear a surgical mask in public because most do not wear them right and may actually contaminate the mask taking them off and on. People with ME that wish to wear a mask in public should be trained by a health care provider. You may wish to buy a N95 mask from a supply store.

Helpful H1N1 Websites

Government of Ontario:

<http://www.health.gov.on.ca/en/ccom/flu/>

City of Toronto Pictorials on Handwashing and Proper Coughing Techniques:

www.toronto.ca/health/cdc/resources/index.htm



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YOUR HEALTH

Flu Vaccination and Chronic Fatigue Syndrome

Printed with permission from Dr. Alison Bested

Greetings! As we enter the flu season, I am writing to you about the flu vaccine as my patients with Chronic Fatigue Syndrome (M.E.) often ask me whether or not they should have it. This depends on a number of factors:

- If you are allergic to eggs, you should not get a flu shot as the vaccine contains egg protein.
- If you had the vaccine in the past and did not have any problems with it, then probably you would tolerate it this time.
- If you have never had it before, then the first question is whether you need it. If you are totally isolated in your own home and your caregivers and family are very aware that they should not come to visit you or care for you if they are ill, then your risk of exposure is minimal.
- If you go outside your home, then you could take the following precautions: Take a disposable paper mask with you if you have to visit public places, e.g. doctors' offices, churches, stores, etc. If anyone is coughing then put your mask on immediately so that you do not breathe in viral particles. Try to keep your hands off your face, especially after coming into contact with another person (e.g. shaking hands) or an object just used by another person (e.g. a pen), so that you do not transfer viruses from your fingers to your eyes and nose. These are easy entry routes for viruses into your body.

If you decide you would like to be vaccinated, then I recommend starting with an injection of one third the usual adult dose. If there are no side effects, then the same dose can be repeated in a month's time, and the same again after one further month. The reason for

this is that physicians specializing in CFS, including myself, have reported cases of flu symptoms in some patients with CFS for 4 or more weeks after the full dose of flu vaccine has been given.

It is unknown whether patients with Fibromyalgia or Environmental Sensitivities / intolerances are more prone to such a response. However, overlap of these conditions with CFS has been reported in the medical literature, and so caution is probably wise.

Having symptoms for this length of time is not normal after a flu shot. It is called an adverse vaccine event and needs to be reported to the Department of Health. There is an Adverse Vaccine Event Form that must be filled out by the doctor. Each region has its own Department of Public Health (in Toronto, 416 392-1250).

All the best to you and yours,

Dr. Alison Bested,
EHC Staff Physician and Hematopathologist

Editor's note: Some additional tips for the winter season:

- ***Wash your hands with warm, soapy water immediately upon returning home after being out among the general public***
- ***Wash your hands before eating finger foods in a restaurant***
- ***Magazines in a doctor's office and door knobs in places outside of your home are just some of the places that are covered in germs; so carry a package of 'Wet Ones' or an antibacterial wash***
- ***Because some of us have shallow breathing, if you do get a cold, remember to do deep breathing exercises (3 deep breathes at a time) and cough up the sputum.***