

H1N1 Influenza Virus, H1N1 Vaccine and Mitochondrial Disease

There have been questions regarding recommendations about people with mitochondrial disease receiving the H1N1 vaccine. The Scientific and Medical Advisory Board (SMAB) of the UMDF did discuss the issue in great detail and these comments reflect the board's discussion. Much of the factual information has been obtained from governmental websites.

The H1N1 virus, also called "the swine flu" typically causes fever, cold symptoms (cough, sore throat, runny or stuffy nose), body aches, loss of appetite, and headache. As with any fever, chills may be present. Fatigue is part of most flu illnesses. Vomiting and diarrhea are reported in some and there are now cases where people have respiratory symptoms without a fever. These symptoms range from mild to severe. There are some people that get sick, but never are sick enough to think about seeing a doctor, whereas others with the same virus will die as a result of their infection. At this point it is not possible to know if the infection will spread to epidemic proportions, or if the virus, which now seems as "bad" as most influenza viruses but no worse, will shift to a strain that will cause more or less severe disease.

If you think anyone in the family may have the H1N1 virus, we advise that you seek out immediate medical attention. As part of general medical practice, both fever and dehydration should be treated with standard medical management. Sometimes bedrest, ibuprofen or acetaminophen and fluids are what will be recommended. Use of antiviral medication is given for more severe cases (which are believed to be safe in those with a mitochondrial disorder). For those people that have shown to be susceptible to regression after dehydration, the use of IV hydration and appropriate IV rehydration therapies is reasonable. Aspirin should be avoided.

Immunization for the H1N1 is now available. The immunization comes as a live attenuated product delivered by spraying it into the nose and as a killed form, which is delivered by injection. The nasal form (live attenuated vaccine) is not recommended for people with chronic health problems, but can be used in people 2-49 years of age that are healthy (such as healthy family members). The inactivated (dead virus) vaccine contains the preservative thimerosal, which was investigated because of the concern it was linked for causing autism. However, in 2004 the experts at the Institute of Medicine concluded there was no evidence of this and further research has indicated there is no health risk or link to autism. It is this inactivated (dead virus) vaccine that is being recommended for those with health problems, which would include mitochondrial disease.

It is important to know that it takes several weeks after the immunization is given for the body to build up immunity against the virus. The Center for Disease Control's Advisory Committee on Immunization Practices has recommended that certain groups receive the 2009 H1N1 vaccine when it first becomes available. These target groups include pregnant women, people who live with or care for children younger than 6 months of age, healthcare personnel, persons between the ages of 6 months and 24 years old,

and people ages of 25 through 64 years of age who are at higher risk for 2009 H1N1 because of chronic health disorders or compromised immune systems. The government is not recommending the immunization for those less than six months of age. For those under 9 years of age the recommendation is two doses of the vaccine separated by four weeks. The group of healthy people between 25-64 years of age are not in the recommended category for immunization because they are less likely to have a bad outcome if they get an H1N1 influenza viral infection.

It is reasonable to believe that an H1N1 infection, or any influenza infection in a child with a mitochondrial disease will be worse than that of an otherwise healthy person. The presence of a fever, reduced food intake, risk of dehydration in addition other parts of the body's cytokine response to the flu will result in a higher risk of injury and subsequent mitochondrial dysfunction that would likely occur in a healthy person. As with any influenza, a certain percentage of infected people will die. Historically this has been the elderly and those that are already ill. The concern among doctors who care for children and adults with mitochondrial disease is that because of the frail state, parents (or affected adults) will choose not to get immunized for fear that the vaccine will make them sick. Understanding the possible risks and the possible benefits should help alleviate this fear.

The vaccine given for the 1976 swine flu (a different strain -- so if you were immunized in 1976 it does not help this year) was possibly causally linked to Guillain-Barré syndrome (GBS) in a small minority --- 450 cases for the 45 million people that got the shot, or about 1 in 100,000. This is a paralyzing disorder that is now treatable (and most people that got this disorder did recover). However in 1976 there were no therapies and 30-40 of those 450 people died. It has never been proven that the vaccine caused the increase in GBS. I have spoken with senior scientists that are convinced there was a link and those that truly believe there was no link. Even after more than 30 years this has not been resolved in the scientific community. In the studies of vaccines that followed the 1976 vaccine, no clear answer has emerged and the number the government decided upon is that the risk is on the order of one in one million. Because of this situation it is recommended that people that have ever had GBS in the past do not get the vaccine. This one in one million risk (or one in 100,000 if you chose that number) needs to be considered along side of the risk of death and disability caused by the flu itself. There have been 10-11 deaths in children this week alone from the swine flu, with 86 confirmed pediatric deaths since the swine flu began being tracked in April 2009. Two-thirds of the hospitalizations in children have been in those with underlying medical problems.

This vaccine has been tested in children and adults using standard methods. There is no evidence that this vaccine will result in any more adverse reactions than other influenza vaccines. There are no special concerns about this vaccine in particular that are worrisome. Waiting to see if the H1N1 virus will cause an epidemic before making a decision about getting the vaccine (or your child) is the wrong strategy. By the time we know if this is an epidemic, given the month or so it takes to achieve immunity, it will be too late. It is easy to find information on the web that will cause you (or me) to question

vaccine safety but when you read past the questions of concern, there are no clear data to support the concern.

There is no way to prevent getting the flu. Of course common sense and strict hand washing are important, but unless you live by yourself and never have contact with another person, you will be exposed to people, and the 100 people every person came into contact with that day.

It is simply not possible to make the blanket recommendation that “all children and adults with mitochondrial disease get the H1N1 immunization.” That is a decision between you and your doctor. In the last several months almost all of my patients (and their families) have asked me if I recommend the vaccine and I have said to all of them so far “I recommend the H1N1 and the regular flu vaccine in your situation.” In addition I have not told a patient they should not receive the vaccine. I am not sure what I will say with the next patient, but to date all have had my recommendation to get the vaccine.

In summary, any influenza poses more of a health risk to a person with mitochondrial disease than to an otherwise healthy person. There is no evidence that the H1N1 vaccine poses a risk of injury above and beyond other influenza vaccines (which I have been recommending to my patients for years). If there is an influenza epidemic caused by the H1N1 virus (or other virus that is covered by the regular seasonal flu vaccine) several months from now, getting the vaccine in the middle of the epidemic will likely not be very helpful. It is everyone’s hope there is no epidemic. But if there is an epidemic, those having received vaccination will have the necessary protection. There is a lot of good information in the web, which can be found by going to your search engine and typing “H1N1 Virus Vaccine”. The CDC.GOV website can give you up-to-date information about the influenza situation and immunizations.

On a personal note, the vaccine just rolled into Cleveland today. My wife just got her H1N1 vaccine when she went into work this evening, I will get mine hopefully when I return to work and we are awaiting instructions from the pediatrician so I can get all my children immunized against the swine flu ASAP (they all have gotten immunized against the seasonal flu).

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