

INSTRUCTIONS FOR

SAMPLE LETTER TO FAMILY MEMBERS REGARDING SUSCEPTIBILITY TO MH

Attached is a sample letter for use in notifying family members about the possibility of MH susceptibility. It may be used as is by filling in the appropriate spaces, or you may use it as a guide for writing your own letter.

MHAUS recommends ordering the following to go with the letter:

Patient Guide to Malignant Hyperthermia in an Anesthesia Setting
Malignant Hyperthermia Susceptible patient wallet card

❖ If **you** had the MH episode, MHAUS suggests notifying your:

Parents	First Cousins
Children	Nieces
Brothers	Nephews
Sisters	Aunts
	Uncles

❖ If **a child** had the MH episode, MHAUS suggests notifying relatives of both sides of the child's family:

Parents	Aunts
Grandparents	Uncles
Brothers	First Cousins
Sisters	
Nieces	
Nephews	

Dear

I am writing to let you know about the potential susceptibility to malignant hyperthermia in our family. We have discovered a genetic trait, which could have a potentially tragic effect on even distant relatives if they require general anesthesia for surgery or diagnostic tests.

We learned about this when _____ was given a commonly used general anesthetic and then had a life-threatening reaction. Although we didn't realize it, _____ was at risk for developing these complications because of an unusual hereditary muscle disorder.

This disorder makes a person susceptible to developing a chain reaction of symptoms (a syndrome) called malignant hyperthermia (MH). (Don't be over concerned about the word "malignant" – MH has nothing to do with cancer.) MH occurs unpredictably, but most often when a susceptible individual is given the drugs that "trigger" MH. **The triggering drugs are: *volatile inhalation anesthetics and succinylcholine, a drug that usually produces transient weakness.*** Episodes of MH have been reported outside of surgery triggered by what are called "awake triggers". You can find more information about "awake triggers" on the MHAUS website.

The reaction includes a variety of abnormalities including: Increased amounts of carbon dioxide expelled by rapid and deep breathing (hyperventilation); dramatic changes in the acid content of the blood (which can cause irritation to the heart and possible cardiac arrest); muscle rigidity; breakdown of muscle, as indicated by very dark urine; and high body temperature (often a late sign).

This syndrome is **reversible** if the operating team is prepared to act quickly. And, the severe problems associated with the syndrome are **preventable** if doctors know in advance of their patient's potential MH susceptibility and take certain precautions.

Although MH is uncommon in the general population, the odds are quite high for family members of known susceptible patients to also have the trait. Most MH susceptible parents transmit the trait to about half of their offspring. It's very important to note that more than 50% of MH-susceptible patients had general anesthesia on at least twice before experienced MH complications. **You should not assume you are safe because you have had uneventful anesthetics.**

The Malignant Hyperthermia Association of the United States (MHAUS), a non-profit educational organization that provides a variety of information materials about MH and what you can do.

Right now there are several steps you should take:

- Please let me know about any anesthetic reactions you or others in the family have experienced. Has anyone in the family died "mysteriously" during or following surgery? This information can help determine which family line carries the MH trait.
- Notify your own doctors about your potential susceptibility. MHAUS can provide you with literature to give them.
- Notify school nurses and teachers and make a note in your children's medical records.

- Contact hospitals in your area to be sure that they stock the antidote drug, **dantrolene sodium for injection**, and that they are prepared to care for your family in an emergency. MHAUS has a form letter you can use for this purpose. Both the Emergency Department and the Anesthesia Department need to be prepared to treat MH susceptible patients DIFFERENTLY than other patients.
- Consider obtaining a medical ID tag such as a bracelet or necklace from MedicAlert Foundation (800-432-5378).

At present, there is only one accurate diagnostic test for MH that can show that you or your relative is NOT at increased risk of MH complications. This involves traveling to a MH Diagnostic Center to have a muscle biopsy. MHAUS can send you more information about the test and a list of the testing sites in the United States which perform it by contacting: **MHAUS, PO Box 1069, Sherburne NY 13460-1069 / 1-800-986-4287 or www.mhaus.org**.

A blood test, that can be ordered by your PCP and sent through the mail, may find a change in your genes that has been recognized to be a cause of MH. If you do have a genetic change that could produce MH, others in your family can be tested for the same genetic change for about 1/10 the cost of examining the entire ryanodine receptor type one gene.

If you believe you have had MH, especially if you have had test results confirming MH susceptibility you should consider joining the North American **MH Registry** of MHAUS, www.mhaus.org/registry. You are welcome to call the MH Registry at 800-274-7899 during business hours. The mailing address of the MH Registry is NAMHR, UPMC Mercy Hospital Building B, 8th Floor, Rm 8522-3, 1400 Locust St., Pittsburgh, PA 15219.

Sincerely,