

FREQUENTLY ASKED QUESTIONS

Why join MH Registry (NAMHR)?

Help research about this condition.

Put information about your muscle condition where you can easily get it.

Who should join the NAMHR?

You must live in the USA or Canada and read English to use this method to join the NAMHR.

Anyone who has experienced an increase in metabolism during general anesthesia,

Anyone who has had muscle injury (increased creatine kinase) during or after general anesthesia,

Anyone who has had heat stroke (or severe muscle injury after exercise),

Anyone who has had muscle pain or weakness with increased creatine kinase after exposure to medications that reduce cholesterol in the blood,

Anyone who has had a muscle contracture test (CHCT or IVCT),

Anyone who had a genetic test of MH susceptibility should join the NAMHR, no matter what the result of the test was,

Anyone who has the diagnosis of central core disease or another myopathy, or

Anyone who has a blood relative with the above problems is welcome to join the NAMHR.

What does it cost me?

A little of your time; NONE of your money.

What does it do for me?

Joining NAMHR supports studies of MH in people and allows us to contact you about future research projects.

Who benefits?

Those who want to know more about MH; researchers and people with this condition and their families.

Possible additional benefits:

You can use the Release of Information Form see (www.mhaus.org/registry/downloads#forPatients) to request in writing that we send a short report of your information that is maintained in the NAMHR to your health care provider.

Is joining MHAUS the same as joining NAMHR?

No. MHAUS is the not-for-profit organization that sponsors NAMHR. NAMHR is a research registry. Joining the NAMHR does not make you a member of MHAUS. Go to www.mhaus.org to find out about MHAUS membership.

Will NAMHR send me a medic-alert tag?

No. You can get it from Medic Alert. If you are MH susceptible consider getting a medic-alert tag by calling # 800-800-0038 and keeping it on your person. There is a charge by Medic Alert for this service.

Will NAMHR help me get tested for MH Susceptibility?

You and your personal physician have to arrange for your testing. See (<http://www.mhaus.org/testing/centers>) for addresses of genetic testing labs and muscle contracture testing centers. If you request it, NAMHR will send the information you have put into the Registry to your physician under the Release of Information Form. (see www.mhaus.org/registry/downloads#forPatients.)

What you should know:

The North American MH Registry (NAMHR) was started in 1987 to collect reports of clinical malignant hyperthermia (MH) events and MH diagnostic tests.

It can act as a central repository of information concerning your MH susceptibility status and to support MH research.

See www.mhaus.org/registry/research/publications to read about the research reports that have been produced from data in the NAMHR. You can read more about the history of the NAMHR at <http://www.mhaus.org/registry>.

People still die from MH during anesthesia in the Operating Room and after surgery is over. Rarely, people can die from MH after admission to the Emergency Room for treatment of heat illness.

Recording histories like yours in the NAMHR helps us to understand MH. Recording the histories of the involved families can be the foundation of better diagnostic testing for susceptibility to the MH syndrome.

Because of the work of the MH Diagnostic Muscle Contracture Testing Centers and the NAMHR, clinical diagnostic testing for MH susceptibility can now be performed on blood. See www.mhaus.org/testing for the addresses of the genetic laboratories that perform

this test. Genetic testing can confirm the diagnosis of MH susceptible, but only muscle contracture testing can at present confirm the diagnosis of NOT MH susceptible.

The NAMHR is a research registry. Personal health information of the people who join the NAMHR is never released by the NAMHR to investigators. The NAMHR staff may sometimes send you an invitation to join a study when you have joined the NAMHR.

The NAMHR staff will usually send a postcard once a year to all who joined the NAMHR to check your address and to give you the opportunity to update your information in the NAMHR. Personal health information will only be released to your doctors when you specifically request it.

A goal of the NAMHR is to collect detailed information about all of the anesthetics that people who believe they are MH susceptible have experienced. Similarly people who are proven to be NOT MH susceptible (MHN) by muscle contracture testing have important information for the NAMHR. MHN people are important control subjects for future research. We want to know as much as possible about the anesthetic experiences of MHN people.

People with muscle diseases may not be sure if they should worry about MH or not. The NAMHR would like to collect as much information about the anesthetic experiences and diagnostic results with regard to any muscular disease and to daily activities of people with muscle disease as possible.

What you should do to help yourself and your family?

Pursue diagnostic testing of your muscular condition as directed by your personal physician. Record the results of diagnostic testing in the NAMHR with your medical and anesthetic history.

Encourage your relatives to do the same, including joining the NAMHR as research subjects.

Update your contact information and your medical history yearly in the NAMHR by contacting the address at the beginning of this form.

If you are MH susceptible consider getting a medic-alert tag by calling # 800-800-0038 and keeping it on your person. There is a charge by Medic Alert for this service.

What can you hope that joining NAMHR will do?

Joining the NAMHR is the most important action that you can take to help advance understanding of MH and related conditions.

NAMHR will keep your personal information confidential unless you make a request in writing for the NAMHR to send a report of the information you have given to NAMHR to a person you chose, such as your health care provider.