

*The North American Malignant Hyperthermia Registry*

**Report of Malignant Hyperthermia Research Subject**

**Already Known As**

**Malignant Hyperthermia Susceptible**

**(“AKA Report”)**

**INSTRUCTIONS:**

*This form is to be filled out by the person to be registered and their anesthesiologist/health care provider.*

1. To register your name with the North American Malignant Hyperthermia Registry, sign the consent form for release of information by you and your physician to the North American Malignant Hyperthermia Registry and for release of information by the North American Malignant Hyperthermia Registry to your future physicians. If both parents of a child who experienced an episode of MH wish to be registered, then separate consent forms must be signed for each parent.
2. You can answer all questions except possibly 17-20 and 29-40. You may need to consult with your anesthesiologist or other physician responsible for diagnosing you as MH susceptible for assistance.
3. Send this AKA report to the anesthesiologist or other physician responsible for diagnosing you as MH susceptible. Please ask this physician to complete the rest of this form (questions 17-20 and 29-40). If this physician is not available, fill out as much of the form as you can.
4. Send this form and all signed consent forms directly to the North American MH Registry (address at bottom of this page). You will need to call the NAMHR office at (888) 274-7899 and speak to Dr. Gravenstein or one of the registry staff to confirm your consent by conversation over the phone. Each person who signed a consent form will need to call the North American MH Registry to confirm that consent by conversation on the telephone as well.
5. Information sent to the North American MH Registry (NAMHR) will remain confidential. Patient specific information will only be accessible by people specifically designated by the research subject.

**Return original completed form to:**

The North American Malignant Hyperthermia Registry  
University of Florida  
Department of Anesthesiology



8. Weight at the time of your MH episode:

\_\_\_\_.\_\_\_\_ kilograms OR \_\_\_\_ lbs

9. Height at the time of your MH episode:

\_\_\_\_\_ cm OR \_\_\_\_ ft \_\_\_\_ inches

10. Date of subject's birth

\_\_\_\_-\_\_\_\_-\_\_\_\_ \ \_\_\_\_ \ \_\_\_\_  
 year month day

11. Race:

*check as many as apply*

*(data utilized for demographic purposes only)*

- Caucasian
- African
- Hispanic
- East Asian
- African-American
- South Asian
- Native American
- Middle Eastern
- Hawaiian or Pacific Islander
- other (*specify*): \_\_\_\_\_

12. Any previous North American MH Registry numbers associated with the subject. That is, AMRA, AKA, close relative's reports, etc.

- a. \_\_\_\_\_ Comment \_\_\_\_\_
- b. \_\_\_\_\_ Comment \_\_\_\_\_
- c. \_\_\_\_\_ Comment \_\_\_\_\_

**FAMILY IDENTIFICATION** (*to be completed by the research subject or subject's guardian*)

13. Does the subject have minor children or siblings under the age of 6 and does this minor child's parent or guardian consent to the child being in the Registry?

*check one*  yes  no

no

*If yes, please complete below for all children under the age of 6*

a. **name**

\_\_\_\_\_ last first middle

Date of birth



**e. name**

\_\_\_\_\_ last

\_\_\_\_\_ first

\_\_\_\_\_ middle

Date of birth

\_\_\_\_ \ \_\_\_\_ \ \_\_\_\_  
year month day

Is this the child or the sibling of the research subject?

*check one* child sibling

14. Has consent been obtained to enter the names of children or siblings ages 6 through 17, or ages 18 and over, of the index research subject into the Registry?

**NOTE: CONSENT MUST BE OBTAINED FROM EACH CHILD/SIBLING OVER 18 YEARS OF AGE FOR WHOM YOU ENTER THIS DATA (If the child/ sibling is deceased, the following data may be entered with the consent of the next of kin\*. If the child is under 18 years of age, consent must be obtained from the child's parent or guardian).**

\* check your local/state regulations regarding the definition of next of kin

*check one*     yes     no

*If yes, complete below for all individuals for whom consent has been obtained*

**a. name**

\_\_\_\_\_ last

\_\_\_\_\_ first

\_\_\_\_\_ middle

Date of birth

\_\_\_\_ \ \_\_\_\_ \ \_\_\_\_  
year month day

Is this the child or the sibling of the index research subject?

*check one* child sibling**b. name**

\_\_\_\_\_ last

\_\_\_\_\_ first

\_\_\_\_\_ middle

Date of birth

\_\_\_\_ \ \_\_\_\_ \ \_\_\_\_  
year month day

Is this the child or the sibling of the index research subject?

*check one*

child

sibling

c. **name**

\_\_\_\_\_

last

first

middle

Date of birth

\_\_\_\_ \ \_\_\_\_ \ \_\_\_\_

year

month

day

Is this the child or the sibling of the index research subject?

*check one*

child

sibling

d. **name**

\_\_\_\_\_

last

first

middle

Date of birth

\_\_\_\_ \ \_\_\_\_ \ \_\_\_\_

year

month

day

Is this the child or the sibling of the index research subject?

*check one*

child

sibling

15. Has consent been obtained to enter the names of the parents of the research subject? If the index research subject is your child, your information goes in this section.

*check one*     yes     no

*If yes, complete below*

**NOTE: CONSENT MUST BE OBTAINED FROM EACH PARENT FOR WHOM YOU ENTER**

**THIS DATA. If the parent is deceased, the following data may be entered regardless of consent status.**

a. Mother of the index research subject

\_\_\_\_\_

last

first

middle

Date of mother's birth

\_\_\_\_ \ \_\_\_\_ \ \_\_\_\_

year

month

day

Mother's maiden name \_\_\_\_\_  
last

b. Father of the index research subject

\_\_\_\_\_ last \_\_\_\_\_ first \_\_\_\_\_ middle  
Date of father's birth  
\_\_\_\_ \ \_\_\_\_ \ \_\_\_\_  
year month day

## 16. Family History Table

*Key to Family History table (below)*

Relationship to Subject	Known Medical Problems
a. child	1. fatal MH
b. grandchild	2. survived fulminant MH event
c. brother/sister	3. possible MH event
d. half-sibling results	4. MH family history (only for those relatives with CHCT)
e. niece/nephew	5. perioperative death - not thought to be MH
f. mother	6. perioperative death - etiology undetermined
g. maternal grandparent	7. S.I.D.S. or cot death
h. maternal aunt/uncle	8. Sudden death - unknown cause, age 1.5 to 45 yrs
j. maternal first cousin	9. heat stroke
k. maternal second cousin	10. neurolept malignant syndrome
m. maternal - other	11. myopathy
n. father	12. idiopathic creatine kinase elevation
o. paternal grandparent (Syndrome)	13. CFIDS (Chronic Fatigue and Immune Dysfunction Syndrome)
p. paternal aunt/uncle	14. muscle pain, weakness or fever with exercise
q. paternal first cousin	15. episodic dark urine and muscle pain
r. paternal second cousin	16. none of the above
s. paternal - other	17. unknown
t. relative by marriage	
u. other blood relative	



**FAMILY HISTORY**

21. Family history is positive for:

*Check all applicable*

- malignant hyperthermia
- masseter spasm
- intraoperative death not thought to be MH
- sudden infant death syndrome or cot death
- sudden death from unknown cause at < 45 year >1.5 years
- heatstroke
- neurolept malignant syndrome
- intolerance to heat
- chronic muscle pain
- frequent muscle cramps
- chronic muscle weakness
- exercise intolerance due to muscle pain, weakness or fever
- episodes of dark urine and muscle pain
- myopathies *specify type; write unknown if not known:* \_\_\_\_\_
- idiopathic creatine kinase elevation
- diabetes
- none of the above
- unknown
- other (*specify*) \_\_\_\_\_ .

**MEDICAL HISTORY**

22. Does the subject have any of the following?

*check all applicable*

- muscle weakness interferes with daily activity at least once/week
- muscle cramps or pain interfere with daily activity at least once/week
- cola colored urine
- heat stroke or heat prostration
- oral (or rectal/axillary equivalent) fever >38.6°C or 101.4 ° F at least 6 times/year without medical cause
- recent generalized infection  
If there was infection, how long ago was it? \_\_\_ (days)
- recent use of cholesterol lowering drugs  
If so, which drug \_\_\_\_\_, and when was it last ingested? \_\_\_ (days)
- a regular regimen of physical activity?  
If so, when was the last work-out? \_\_\_ (days)
- ingestion of any medicine to improve muscular performance
- intolerance to heat
- exercise intolerance due to muscle pain, weakness or fever
- diabetes
- none of the above

unknown

other (*specify*): \_\_\_\_\_

23. Has the subject ever had physical findings of:  
*check all applicable*

increased muscle tone

decreased muscle tone

generalized muscle weakness

myopathy *specify type; write unknown if not known:*

\_\_\_\_\_

ptosis

strabismus

hiatal hernia

inguinal hernia

umbilical hernia

undescended testes

clubbed foot

joint hypermobility

kyphoscoliosis (moderate or severe; curve >45°)

pectus carinatum

winged scapulae

skeletal fractures (more than 2)

gallstones

kidney stones

laryngeal papillomas

other (*specify*): \_\_\_\_\_

none of the above

unknown

### **ANESTHETIC HISTORY**

24. How many times was this subject anesthetized prior to this evaluation?

— —

unknown

*Skip to question 28 if the response is zero or unknown.*

25. How many were general anesthetics?

— —

unknown

26. Indicate the number of anesthetics with the following agents:

\_\_\_ volatile agents without succinylcholine

\_\_\_ volatile agents with succinylcholine

\_\_\_ succinylcholine without other known triggering agents



- |  |   |
|--|---|
| <input type="checkbox"/> unknown                               | <input type="checkbox"/> neostigmine (Prostigmin)   |
| <input type="checkbox"/> <b>NO</b> potent volatile anesthetics | <input type="checkbox"/> physostigmine (Antilirium) |
| <input type="checkbox"/> sevoflurane (Ultane)                  | <input type="checkbox"/> pyridostigmine (Mestinon)  |
| <input type="checkbox"/> desflurane (Suprane)                  |   |
| <input type="checkbox"/> isoflurane (Forane)                   | <input type="checkbox"/> bupivacaine (Marcaine)     |
| <input type="checkbox"/> nitrous oxide                         | <input type="checkbox"/> levo-bupivacaine           |
|  | <input type="checkbox"/> choroprocaine (Nesacaine)  |
| <input type="checkbox"/> nalbuphine (Nubain)                   | <input type="checkbox"/> cocaine                    |
| <input type="checkbox"/> naloxone (Narcan)                     | <input type="checkbox"/> etidocaine (Duranest)      |
|  | <input type="checkbox"/> lidocaine (Xylocaine)      |
| <input type="checkbox"/> atracurium (Tracrium)                 | <input type="checkbox"/> mepivacaine (Carbocaine)   |
| <input type="checkbox"/> cisatracurium (Nimbex)                | <input type="checkbox"/> prilocaine (Citanest)      |
| <input type="checkbox"/> rocuronium (Zemuron)                  | <input type="checkbox"/> procaine (Novocain)        |
| <input type="checkbox"/> vecuronium (Norcuron)                 | <input type="checkbox"/> ropivacaine (Naropin)      |
| <input type="checkbox"/> pancuronium (Pavulon)                 | <input type="checkbox"/> tetracaine (Pontocaine)    |
| <input type="checkbox"/> other NMB                             |   |
| <input type="checkbox"/> <b>IM</b> succinylcholine (Anectine)  | <input type="checkbox"/> epinephrine                |
| <input type="checkbox"/> <b>IV</b> succinylcholine (Anectine)  | <input type="checkbox"/> ephedrine                  |
| <input type="checkbox"/> <b>NO</b> succinylcholine             | <input type="checkbox"/> neosynephrine              |
| <input type="checkbox"/> edrophonium (Tensilon)                |   |
| <input type="checkbox"/> other ( <i>specify</i> ): _____       |   |

30. Signs and abnormal findings during possible or fulminant MH

Abnormal signs noted by the attending anesthesiologist or other physician.

**RANK in order of appearance. NUMBER do not check. WRITE ZERO if sign did not occur.**

*(a number may be used more than once if signs were noted simultaneously)*

- masseter spasm: mouth cannot be fully opened, but direct laryngoscopy is possible
- masseter spasm: jaw clamped shut, intubation by direct visualization impossible
- generalized muscular rigidity
- cola colored urine
- tachypnea
- hypercarbia
- cyanosis
- sinus tachycardia
- ventricular tachycardia
- ventricular fibrillation
- elevated temperature
- rapidly increasing temperature
- sweating
- excessive bleeding
- skin mottling
- hypertension > 20% baseline
- other (*specify*): \_\_\_\_\_
- none of the above

31. Abnormal metabolic values during possible or fulminant MH

Most abnormal arterial blood gas after MH was suspected:

- \_\_\_ . \_\_\_ \_\_\_ FiO<sub>2</sub>
- \_\_\_ . \_\_\_ \_\_\_ pH
- \_\_\_ \_\_\_ \_\_\_ PCO<sub>2</sub>
- \_\_\_ \_\_\_ \_\_\_ PO<sub>2</sub>
- \_\_\_ \_\_\_ . \_\_\_ BE (mEq/L) (specify ±)
- \_\_\_ \_\_\_ Bicarbonate (mEq/L)
- \_\_\_ \_\_\_ \_\_\_ time (hours after induction)

peak lactic acid

\_\_\_ . \_\_\_ mmol/L

peak K<sup>+</sup>

\_\_\_ \_\_\_ . \_\_\_ mEq/L or mmol/L

peak post-op creatine kinase\*      first creatine kinase\*      last creatine kinase\*  
\_\_\_\_\_, \_\_\_\_\_ U/L      \_\_\_\_\_, \_\_\_\_\_      \_\_\_\_\_, \_\_\_\_\_

\_\_\_\_ hours after induction      \_\_\_\_ hrs after induction      \_\_\_\_ hrs after induction

**\*(recommended intervals for creatine kinase determination are 0, 6, 12, 24 hours after adverse reaction)**

32. Treatment given for possible or fulminant MH

*check all treatments utilized*

Volatile anesthetics discontinued at time: \_\_\_\_\_ (hours after induction)

Hyperventilation with 100% oxygen

Dantrolene (*type*)

Dantrium

Revonto

Ryanodex

\_\_\_\_\_.\_\_\_\_

Initial dose (mg)

\_\_\_\_

Time of first dose (hours after induction)

\_\_\_\_\_.\_\_\_\_

Total dose (mg)

\_\_\_\_

Time of last dose (Hours after anesthetic induction)

Active cooling

Fluid loading

Furosemide

Mannitol

Bicarbonate

Glucose, insulin

Bretylium

Amrinone

Vasopressor

Lidocaine

Procainamide

Defibrillation

CPR

other (*specify*): \_\_\_\_\_

none of the above

unknown

33. Were any problems noted with the dantrolene administration?

*check one*

yes

no

unknown

*If no, please skip to question 35*

34. What were the observed dantrolene complications?

*check all applicable*

- phlebitis
- excessive secretions
- gastrointestinal upset
- hyperkalemia
- muscle weakness
- respiratory failure
- other *specify*: \_\_\_\_\_

**DNA TESTING** *(to be completed by the physician)*

35. Was a genetic test performed?

*check one*

- yes       no

36. Where was the genetic test done?

\_\_\_\_\_

36a. Is a sample of the DNA stored in the lab?

- yes  
 no

37. When was the genetic test done?

\_\_\_\_\_

38. Which of the RYR1 exons were examined?

\_\_\_\_\_                      \_\_\_\_\_  
\_\_\_\_\_                      \_\_\_\_\_  
\_\_\_\_\_                      \_\_\_\_\_

39. Was any mutation associated with MH or central core disease present?

*check one*       yes       no      *If yes,*

*specify*: \_\_\_\_\_

40a. Were any other sequence variants identified?

*check one*       yes       no      *If yes,*

*specify*: \_\_\_\_\_

40b. Did the subject survive the initial reaction?

*check one*

yes       unknown because of transfer of case during treatment       no

40b. Did the subject survive any subsequent reaction (recrudescence) and recovery?

*check one*

yes       unknown because of transfer of case during treatment       no

**MH DIAGNOSTIC MUSCLE BIOPSY**

*Answer for caffeine halothane contracture test or European IVCT test only. These tests are only done at MH Biopsy centers, and are different from regular pathology biopsies.*

41. Date of diagnostic muscle biopsy

\_\_\_\_ \_ \ \_\_\_\_ \_ \ \_\_\_\_ \_  
year                      month                      day

42. Results

*check one*

- positive—MH susceptible
- negative—not susceptible to MH
- equivocal—MH susceptibility indeterminate

43. Center which performed MH Biopsy (Caffeine Halothane Contracture Test)

*check one*

- Children's Hospital of Oklahoma
- Cleveland Clinic
- Hahnemann University
- Thomas Jefferson University
- Loyola University
- Northwestern University
- Mayo Clinic
- Ottawa Hospital- Civic Campus
- Presbyterian University Hospital (Pittsburgh)
- Toronto General Hospital
- UC-Davis
- UCLA
- Uniformed Services University
- University of Calgary
- University of Florida
- University of Iowa

- University of Manitoba
- University of Massachusetts
- University of Nebraska
- University of South Florida
- University of Texas-Houston
- University of Texas Medical Branch
- University of Washington
- University of Wisconsin
- Wake Forest University
- other (*specify*): \_\_\_\_\_

**44. I certify that the information contained in this report is complete and accurate.**

\_\_\_\_\_  
(Signature of subject submitting this report)

\_\_\_\_ \ \_\_\_\_ \ \_\_\_\_  
year            month        day

**COMMENTS ON SUBJECT**

*Optional*

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