

The North American Malignant Hyperthermia Registry

**MALIGNANT HYPERTHERMIA BIOPSY
and
DIAGNOSTIC CONSULTATION
REPORT**

Version 9.4 (June 2010)

INSTRUCTIONS FOR USE

This form is only to be used by the staff of an MH diagnostic center.

1. Use this form for each patient referred to you for MH evaluation, if they undergo muscle biopsy.
2. If any adult relatives wish to be registered by name, separate consent forms for participation in the Registry must be signed by that relative. If you wish to register a minor under the age of 18, a consent form must be signed by one of the minor's parent or guardian.
3. The Center Director must review and sign this form verifying accuracy before it is submitted to the Registry.
4. Please make a photocopy of the completed form for your records.
5. Submit original completed form to:

The North American Malignant Hyperthermia Registry
UPMC Mercy Hospital
8th Floor, Ermire Building (B)
Room 8522-3
1400 Locust Street
Pittsburgh, PA 15219
MCL2@pitt.edu

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

Biopsy Center Director Signature

___/___/___
year month day

MH BIOPSY AND DIAGNOSTIC CONSULTATION REPORT

Version 9.4

June 2010

Complete this form for each patient referred for MH susceptibility evaluation. The MH muscle biopsy center director must review the completed form before it is returned to the NAMHR.

1. MH muscle biopsy center code number:
see final page for code numbers

PATIENT IDENTIFICATION

2. North American MH Registry Number for this patient (if previously assigned)

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

- | | | | |
|----|-------|---------|-------|
| a. | _____ | Comment | _____ |
| b. | _____ | Comment | _____ |
| c. | _____ | Comment | _____ |

4. Patient's Initials

first middle last

5. Has consent been obtained to enter patient's name into the Registry?

check one

() yes

() no

If yes, please complete a-g on following page.

Note: **DO NOT COMPLETE IF CONSENT HAS NOT BEEN OBTAINED**

a. Patient's name. This is the primary subject

last first middle

b. Patient's previous name

last first middle

c. Patient's maiden name

last

d. Patient's Address

street address

city state/province zip/postal code

country

e. Phone number

(Home) (____) _____ - _____
(Work) (____) _____ - _____

f. Patient e-mail address _____

g. Date of patient's birth

____ \ ____ \ ____

year month day

DEMOGRAPHIC INFORMATION

6. Sex

check one

male

female

7. Weight

____.____ kilograms OR ____ lbs

8. Height

_____ cms OR ____ ft ____ inches

9. Year of patient's birth

10. Race:

check as many as apply

Caucasian

African

Hispanic

East Asian

African-American

South Asian

Native American

Middle Eastern

Hawaiian or Pacific Islander

other (*specify*): _____

11. Body Build

check one

Normal

Lean

Muscular

Obese

Postpartum

Other (*specify*): _____

12. State or province of patient's residence

FAMILY IDENTIFICATION

13. Does the primary 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

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

a. **name**

_____ last _____ first _____ middle

Date of birth

____ \ ____ \ ____
year month day

Is this the child or the sibling of the biopsied patient?

check one

child

sibling

b. **name**

_____ last _____ first _____ middle

Date of birth

____ \ ____ \ ____
year month day

Is this the child or the sibling of the biopsied patient?

check one

child

sibling

c. **name**

_____ last _____ first _____ middle

Date of birth

____ \ ____ \ ____
year month day

Is this the child or the sibling of the biopsied patient?

check one

child

sibling

d. **name**

_____ last _____ first _____ middle

Date of birth

_______________\
year month day

Is this the child or the sibling of the biopsied patient?

check one

child

sibling

e. **name**

_____ last _____ first _____ middle

Date of birth

_______________\
year month day

Is this the child or the sibling of the biopsied patient?

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 biopsied patient 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 biopsied patient?

check one

() child

() sibling

b. **name**

_____ last _____ first _____ middle

Date of birth

____ \ ____ \ ____
year month day

Is this the child or the sibling of the biopsied patient?

check one

() child

() sibling

c. **name**

_____ last _____ first _____ middle

Date of birth

____ \ ____ \ ____
year month day

Is this the child or the sibling of the biopsied patient?

check one

() child

() sibling

d. **name**

last first middle

Date of birth

____ \ ____ \ ____

year month day

Is this the child or the sibling of the biopsied patient?

check one

child

sibling

15. Has consent been obtained to enter the names of the parents of a biopsied patient?

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 biopsied patient

last first middle

Date of mother's birth

____ \ ____ \ ____

year month day

Mother's maiden name

last

b. Father of biopsied patient

last first middle

Date of father's birth

____ \ ____ \ ____

year month day

16. Family History Table

Key to Family History table (below)

Relationship to Patient	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	4. MH family history (use only for those relatives with CHCT results)
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	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. diabetes
s. paternal – other	17. none of the above
t. relative by marriage	18. unknown
u. other blood relative	

Please complete one row for each relative for whom relevant medical history is known.

<u>Relative's Initials</u>	<u>Registry Number</u> <i>Leave blank if relative not registered. Insert "?" if relative registered but number not known</i>	<u>Relationship to Patient</u> <i>Select one letter from left-hand column above.</i>	<u>Sex</u> <i>M=Male F=Female</i>	<u>Medical Problems</u> <i>Select one or ore numbers from right-hand or column above.</i>	<u>CHCT Test Result</u> <i>Write "pos", "neg", "equiv", "unknown", "not performed", "other"</i>	<u>Genetic Result</u> <i>Specify familial mutation or "neg", "not performed", or "other"</i>
_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____

Do not write in the initials of a relative of the biopsied patient unless the relative or their parent or guardian has signed a consent form for participation in the Registry. If the relative is deceased, the initials may be entered regardless of consent status.

FAMILY HISTORY

16a. Before this episode, was the patient's family history 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
 - Type 1
 - Type 2
- none of the above
- unknown
- other specify _____

MEDICAL HISTORY

17. Does the patient have any of the following complaints?
check all applicable
- muscle weakness interferes with daily activity at least once/week
 - muscle cramps 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
 - Type 1
 - Type 2
 - other (*specify*) _____
 - none of the above
 - unknown

18. Has patient 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 $>45^\circ$)

pectus carinatum

winged scapulae

skeletal fractures (more than 2)

gallstones

kidney stones

laryngeal papillomas

other (*specify*): _____

none of the above

unknown

ANESTHETIC HISTORY

19. How many times was this patient anesthetized prior to this evaluation?

___ ___ () unknown but > 0 () unknown
Skip to question 35 if the response is zero

20. How many were general anesthetics?

___ ___ () unknown but > 0 () unknown

21. Indicate the number of anesthetics with the following agents

___ ___ volatile agents without succinylcholine
___ ___ volatile agents with succinylcholine
___ ___ succinylcholine without other known triggering agents

22. Year of most recent anesthetic (excluding present evaluation)

___ ___ ___ ___ () unknown

23. Were unusual metabolic responses noted during prior anesthetics?

check one
() yes
() no
() unknown

23a. Were unusual metabolic or muscular responses noted during prior anesthetics?

check one
() no
() yes
() unknown

24. Was there delayed awakening from previous general anesthetics?

check one
() yes
() no
() unknown

25. How many anesthetics were suspect for possible MH (director's opinion)?

___ ___

26. How many fulminant MH episodes occurred (director's opinion)?

___ ___

Skip to question 35 if the answer to questions 25 and 26 are zero

- g. Was the procedure an emergency?
check one
 yes
 no
 unknown
- g (a). Was the procedure performed outside a hospital?
check one
 no
 yes
 ambulatory surgery center
 office
 unknown
- g (b). Did this adverse reaction occur without exposure to anesthetic?
check one
 no
 yes
 unknown
- g (c). Was the environment hot when this reaction occurred?
check one
 no
 yes
If yes how hot? ___ . ___ C or ___ . ___ F
- h. Was any infection present at the time of this surgery?
check one
 yes
 no
 unknown
- i. If infection was present, what organisms were known to be present?

j. Premedication and anesthetic agents utilized (before reaction occurred):

check all applicable

- | | |
|--|---|
| <input type="checkbox"/> sodium citrated citric acid (Bicitra) | <input type="checkbox"/> sevoflurane (Ultane) |
| <input type="checkbox"/> cimetidine (Tagamet) | <input type="checkbox"/> desflurane (Suprane) |
| <input type="checkbox"/> famotidine (Pepcid) | <input type="checkbox"/> halothane (Fluothane) |
| <input type="checkbox"/> lansoprazole (Prevacid) | <input type="checkbox"/> enflurane (Ethrane) |
| <input type="checkbox"/> ranitidine (Zantac) | <input type="checkbox"/> isoflurane (Forane) |
| | <input type="checkbox"/> nitrous oxide |
| <input type="checkbox"/> metoclopramide (Reglan) | |
| <input type="checkbox"/> omeprazole (Prilosec) | <input type="checkbox"/> nalbuphine (Nubain) |
| | <input type="checkbox"/> naloxone (Narcan) |
| <input type="checkbox"/> atropine | |
| <input type="checkbox"/> glycopyrrolate (Robinul) | <input type="checkbox"/> atracurium (Tracrium) |
| <input type="checkbox"/> scopolamine (Hyoscine) | <input type="checkbox"/> cisatracurium (Nimbex) |
| | <input type="checkbox"/> mivacurium (Mivacron) |
| <input type="checkbox"/> dolasetron (Anzemet) | <input type="checkbox"/> rocuronium (Zemuron) |
| <input type="checkbox"/> droperidol (Inapsine) | <input type="checkbox"/> vecuronium (Norcuron) |
| <input type="checkbox"/> hydroxyzine (Vistaril) | <input type="checkbox"/> curare |
| <input type="checkbox"/> ondansetron (Zofran) | <input type="checkbox"/> metocurine (Metubine) |
| <input type="checkbox"/> promethazine (Phenergan) | <input type="checkbox"/> pancuronium (Pavulon) |
| | <input type="checkbox"/> pipecuronium (Arduan) |
| <input type="checkbox"/> methohexital (Brevital) | <input type="checkbox"/> other NMB |
| <input type="checkbox"/> pentobarbital (Nembutal) | <input type="checkbox"/> IM succinylcholine (Anectine) |
| <input type="checkbox"/> thiamylal | <input type="checkbox"/> IV succinylcholine (Anectine) |
| <input type="checkbox"/> thiopental (Pentothal) | <input type="checkbox"/> NO succinylcholine |
| | <input type="checkbox"/> edrophonium (Tensilon) |
| <input type="checkbox"/> clonidine (Duraclon) | <input type="checkbox"/> neostigmine (Prostigmin) |
| <input type="checkbox"/> dexmedetomidine | <input type="checkbox"/> physostigmine (Antilirium) |
| <input type="checkbox"/> diazepam (Valium) | <input type="checkbox"/> pyridostigmine (Mestinon) |
| <input type="checkbox"/> lorazepam (Ativan) | |
| <input type="checkbox"/> midazolam (Versed) | <input type="checkbox"/> bupivacaine (Marcaine) |
| | <input type="checkbox"/> levo-bupivacaine |
| <input type="checkbox"/> etomidate (Amidate) | <input type="checkbox"/> chloroprocaine (Nesacaine) |
| <input type="checkbox"/> ketamine (Ketalar) | <input type="checkbox"/> cocaine |
| <input type="checkbox"/> propofol (Diprivan) | <input type="checkbox"/> etidocaine (Duranest) |
| | <input type="checkbox"/> lidocaine (Xylocaine) |
| <input type="checkbox"/> alfentanil (Alfenta) | <input type="checkbox"/> mepivacaine (Carbocaine) |
| <input type="checkbox"/> fentanyl (Sublimaze) | <input type="checkbox"/> prilocaine (Citanest) |
| <input type="checkbox"/> fentanyl and droperidol (Innovar) | <input type="checkbox"/> procaine (Novocain) |
| <input type="checkbox"/> meperidine (Demerol) | <input type="checkbox"/> ropivacaine (Naropin) |
| <input type="checkbox"/> morphine | <input type="checkbox"/> tetracaine (Pontocaine) |
| <input type="checkbox"/> remifentanyl (Ultiva) | |
| <input type="checkbox"/> sufentanil (Sufenta) | <input type="checkbox"/> epinephrine |
| | <input type="checkbox"/> ephedrine |
| <input type="checkbox"/> unknown | <input type="checkbox"/> neosynephrine |
- NO potent volatile anesthetic**
- other (*specify*): _____

- k. Anesthesia induction time
— . — . — (in hours, express parts of an hour using decimal points)
(example – 3 minutes = 0.05)
- l. General anesthetic induction method
check one
 inhalation
 intravenous
 other (specify): _____
 not applicable
- m. Anesthesia duration
— . — . — (in hours, express parts of an hour using decimal points)
(example – 3 minutes = 0.05)
- n. Type of anesthetic prior to adverse metabolic or muscular reaction to anesthesia
check all applicable
 monitored anesthesia care (local standby)
 regional anesthesia
 spinal anesthesia
 epidural anesthesia
 general anesthesia **without** endotracheal intubation
 general anesthesia **with** endotracheal intubation
 tourniquet use
 tourniquet use
 elapsed time after the start of anesthesia tourniquet was inflated
 — . — . — (in hours, express parts of an hour using decimal points)
 (example – 3 minutes = 0.05)
 elapsed time after final release of tourniquet
 — . — . — (in hours, express parts of an hour using decimal points)
 (example – 3 minutes = 0.05)

Patient Monitoring Utilized

o. Monitoring utilized (before reaction occurred):

check all monitoring used

- | | |
|--|---|
| <input type="checkbox"/> blood pressure monitor | <input type="checkbox"/> end-tidal PCO ₂ |
| <input type="checkbox"/> electrocardiograph | <input type="checkbox"/> pulse oximeter |
| <input type="checkbox"/> stethoscope | <input type="checkbox"/> bladder (Foley) catheter |
| <input type="checkbox"/> arterial catheter | |
| <input type="checkbox"/> central venous catheter | |
| <input type="checkbox"/> pulmonary artery catheter | |

temperature probes:

- axillary
- bladder
- esophageal
- nasopharyngeal
- rectal
- skin - electronic
- skin - liquid crystal
- tympanic
- other monitoring (*specify*): _____

p. If a liquid crystal temperature probe was used, did it accurately trend with core temperatures?

check one

- yes
- no

q. Was a forced air or I.V. warming device in use?

check one

- yes
- no
- unknown

Documentation of the Reaction

- r. Abnormal signs judged to be inappropriate 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 intubation possible
- ___ masseter spasm: teeth clamped shut, intubation via direct visualization impossible
- ___ generalized muscular rigidity
- ___ cola colored urine
- ___ tachypnea
- ___ hypercarbia
- ___ cyanosis
- ___ skin mottling
- ___ sinus tachycardia
- ___ ventricular tachycardia
- ___ ventricular fibrillation
- ___ elevated temperature
- ___ rapidly increasing temperature
- ___ sweating
- ___ excessive bleeding
- ___ hypertension > 20% of baseline
- ___ other (*specify*): _____

- s. Signs: Maximum values and times
fill in the blanks

- ___ . ___ time first adverse sign noted (***after induction***)
(in hours, express parts of an hour using decimal points)
(example – 3 minutes = 0.05)
- ___ . ___ time second adverse sign noted (***after induction***)
(in hours, express parts of an hour using decimal points)
(example – 3 minutes = 0.05)
- ___ . ___ maximum temperature noted (°C) **OR**
- ___ . ___ maximum temperature noted (°F)
- ___ . ___ time maximum temperature noted (***after induction***)
(in hours, express parts of an hour using decimal points)
(example – 3 minutes = 0.05)
- ___ . ___ maximum end-tidal PCO₂ noted (mmHg)
- ___ . ___ time maximum end-tidal PCO₂ noted (***after induction***)
(in hours, express parts of an hour using decimal points)
(example – 3 minutes = 0.05)

t. Type of ventilation used at the time hypercarbia was first observed:

check one

() spontaneous

() assisted

() controlled

() not applicable

() unknown

u. Laboratory Evaluation used during the reaction.

Fill in the blanks for all lab tests obtained

Most abnormal arterial blood gas after MH was suspected:

__ . __ __ FiO₂

__ . __ __ pH

__ __ __ PCO₂

__ __ __ liters/minute

__ __ __ PO₂

ventilation at the

__ __ . __ BE (mEq/L) (specify ±)

time of this blood

__ __ Bicarbonate (mEq/L)

gas

__ __ __ Time (*after induction*)

(in hours, express parts of an hour using decimal points)

(example – 3 minutes = 0.05)

peak lactic acid

__ . __ mmol/L

peak K⁺

__ . __ 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)**

serum myoglobin

__ __ , __ __ __ ng/ml

__ __ hours after induction

urine myoglobin

__ __ , __ __ __ mg/L

__ __ hours after induction

PT (prothrombin time)

INR

PTT (partial thromboplastin time)

__ __ seconds

__ . __

__ __ seconds

laboratory upper limit of normal

__ __ __ seconds

laboratory upper limit of normal

__ __ __ seconds

platelet count

__ __ __ , __ __ __

fibrinogen

__ __ __ mg/dl

v. Monitoring utilized (**after** reaction occurred):
check all monitoring used

- | | |
|--|---|
| <input type="checkbox"/> blood pressure monitor | <input type="checkbox"/> end-tidal PCO ₂ |
| <input type="checkbox"/> electrocardiograph | <input type="checkbox"/> pulse oximeter |
| <input type="checkbox"/> stethoscope | <input type="checkbox"/> bladder (Foley) catheter |
| <input type="checkbox"/> arterial catheter | |
| <input type="checkbox"/> central venous catheter | |
| <input type="checkbox"/> pulmonary artery catheter | |

temperature probes:

- axillary
- bladder
- esophageal
- nasopharyngeal
- rectal
- skin – electronic
- skin - liquid crystal
- tympanic
- other monitoring (*specify*):_____

w. Treatment given for possible or fulminant MH
check all treatments utilized; fill in the blanks

- Volatile anesthetics discontinued
 ___ . ___ Time (**after induction**)
 (in hours, express parts of an hour using decimal points)
 (example – 3 minutes = 0.05)

- Anesthesia machine changed
- Anesthesia circuit changed
- Hyperventilation with 100% oxygen
- Dantrolene (Dantrium)

- ___ . ___ Initial dose (mg)
- ___ . ___ Time of first dose (**after induction**)
 (in hours, express parts of an hour using decimal points)
 (example – 3 minutes = 0.05)

- ___ . ___ Total dose (mg)
- ___ . ___ Time of last dose (**after induction**)
 (in hours, express parts of an hour using decimal points)
 (example – 3 minutes = 0.05)

- | | |
|---|---|
| <input type="checkbox"/> Active cooling | <input type="checkbox"/> Fluid loading |
| <input type="checkbox"/> Furosemide | |
| <input type="checkbox"/> Mannitol | <input type="checkbox"/> Bicarbonate |
| <input type="checkbox"/> Glucose, insulin | <input type="checkbox"/> Amrinone |
| <input type="checkbox"/> Bretylium | <input type="checkbox"/> Vasopressor |
| <input type="checkbox"/> Lidocaine | <input type="checkbox"/> Procainamide |
| <input type="checkbox"/> CPR | <input type="checkbox"/> Defibrillation |

- other (*specify*) _____
- none of the above

28. Mark any of the following that were noted after dantrolene was given:
() Decrease in heart rate.
() Decrease in end-tidal carbon dioxide or carbon dioxide tension in blood.
() Decrease in temperature.

If none were noted, please skip to question 35

29. How many minutes after dantrolene administration was the maximum decrease in this sign noted and what was the magnitude of this change?

Heart rate

(_ _ _) minutes

(_ _) (beats/min)

Carbon dioxide

(_ _ _) minutes

(_ _) (mmHg or torr)

Temperature

(_ _ _) minutes

(_ _ . _ °C) or (_ _ _ °F)

30. Were any problems noted with the dantrolene administration?

check one

() yes

() no

If no, please skip to question 32

31. What were the observed dantrolene complications?

check all applicable

() phlebitis

() excessive secretions

() gastrointestinal upset

() hyperkalemia

() muscle weakness

() respiratory failure

() other (*specify*): _____

32. Did the patient develop additional signs or symptoms after initial adequate treatment (recrudescence)?

check one

() yes

() no

If no, please skip to question 35

33. What was the time of the recrudescence?

__ __ : __ __ time (hours after anesthetic induction)

34. Signs of recrudescence that were noted:
(judged to be inappropriate by the attending anesthesiologist or other physician)
RANK in order of appearance.
(a number may be used more than once if signs were noted simultaneously)
- masseter spasm: mouth cannot be fully opened but intubation possible
 - masseter spasm: teeth clamped shut, intubation via direct visualization impossible
 - generalized muscular rigidity
 - cola colored urine
 - tachypnea
 - hypercarbia
 - cyanosis
 - skin mottling
 - sinus tachycardia
 - ventricular tachycardia
 - ventricular fibrillation
 - elevated temperature
 - rapidly increasing temperature
 - sweating
 - excessive bleeding
 - hypertension > 20% of baseline
 - other (*specify*): _____

ADVERSE METABOLIC REACTION TO ANESTHESIA (AMRA) REPORT

35. If an AMRA Report was submitted, did you review it after pertinent anesthesia records were obtained?
check one
() yes
() no
If no, skip to question 57

AMRA number (if known) _____

36. Were errors found in the AMRA Report?
check one
() yes
() no
If yes, specify _____

LABORATORY EXAM:

Serum Creatine Kinase

37. Creatine kinase at the time of evaluation:
___ ___ ___ , ___ ___ ___ U/L
38. Laboratory upper limit of normal for creatine kinase
___ ___ ___ U/L

Muscle Biopsy

39. Was a MH diagnostic muscle biopsy indicated?
check one
 yes
 no
Note: If no, then skip to question 55
40. What was the reason for the MH diagnostic muscle biopsy?
check all applicable
 fulminant MH
 possible MH event (may include MMR), AMRA Report completed
 possible MH event (may include MMR), AMRA Report not completed
 family history of MH
 control
 negative genetic test
location _____
date _____
exons examined _____
 other (*specify*): _____
41. Date of muscle biopsy
___ ___ ___ \ ___ ___ \ ___ ___
year month day
42. Time of anesthetic induction for muscle biopsy
___ ___ : ___ ___ (military time)
43. Time muscle was excised
___ ___ : ___ ___ (military time)
44. Which muscle was biopsied?
check one
 vastus
 rectus abdominus
 gracilis
 other (*specify*): _____

45. Were any medications being taken at the time of biopsy?
check one
 yes
 no

If yes, specify type of medication:

<u>Type of agent</u>	<u>Name of Drug</u>	<u>Hrs. before biopsy</u>
calcium channel blocker	_____	_____
neuroleptic agent	_____	_____
adrenergic agent	_____	_____
lipid lowering agent	_____	_____
other	_____	_____

46. Premedication and anesthetic agents utilized (for biopsy):

check all applicable

- sodium citrated citric acid (Bicitra)
- cimetidine (Tagamet)
- famotidine (Pepcid)
- lansoprazole (Prevacid)
- ranitidine (Zantac)
- metoclopramide (Reglan)
- omeprazole (Prilosec)
- atropine
- glycopyrrolate (Robinul)
- scopolamine (Hyoscine)
- dolasetron (Anzemet)
- droperidol (Inapsine)
- hydroxyzine (Vistaril)
- ondansetron (Zofran)
- promethazine (Phenergan)
- methohexital (Brevital)
- pentobarbital (Nembutal)
- thiamylal
- thiopental (Pentothal)
- clonidine (Duraclon)
- dexmedetomidine
- diazepam (Valium)
- lorazepam (Ativan)
- midazolam (Versed)
- etomidate (Amidate)
- ketamine (Ketalar)
- propofol (Diprivan)
- alfentanil (Alfenta)
- fentanyl (Sublimaze)
- fentanyl and droperidol (Innovar)
- meperidine (Demerol)
- morphine
- remifentanyl (Ultiva)
- sufentanil (Sufenta)
- unknown
- other (*specify*): _____
- nitrous oxide
- flumazenil (Romazicon)
- nalbuphine (Nubain)
- naloxone (Narcan)
- atracurium (Tracrium)
- cisatracurium (Nimbex)
- mivacurium (Mivacron)
- rocuronium (Zemuron)
- vecuronium (Norcuron)
- curare
- metocurine (Metubine)
- pancuronium (Pavulon)
- pipecuronium (Arduan)
- other NMB
- IM** succinylcholine (Anectine)
- IV** succinylcholine (Anectine)
- NO** succinylcholine
- edrophonium (Tensilon)
- neostigmine (Prostigmin)
- physostigmine (Antilirium)
- pyridostigmine (Mestinon)
- bupivacaine (Marcaine)
- levo-bupivacaine
- chlorprocaine (Nesacaine)
- cocaine
- etidocaine (Duranest)
- lidocaine (Xylocaine)
- mepivacaine (Carbocaine)
- prilocaine (Citanest)
- procaine (Novocain)
- ropivacaine (Naropin)
- tetracaine (Pontocaine)
- epinephrine
- ephedrine
- neosynephrine

- 46a. Type of anesthetic used for biopsy:
check all applicable
- monitored anesthesia care (local standby)
 - regional anesthesia
 - spinal anesthesia
 - epidural anesthesia
 - general anesthesia **without** endotracheal intubation
 - general anesthesia **with** endotracheal intubation
 - general anesthesia with a face mask
 - general anesthesia with a laryngeal mask airway

HISTOLOGY

47. Was muscle histology performed?
check one
- yes
 - no
- If no, skip to question 48*
48. The muscle histology result was:
check one
- normal
 - abnormal
 - equivocal
- If normal, skip to question 48*
49. What were the abnormal histologic findings?
check one
- diffusely distributed internal nuclei
 - other (*specify abnormality, write pending if results not available*)
-
50. Was muscle histochemistry performed?
check one
- yes
 - no
- If no, skip to question 51*
51. The muscle histochemistry result was:
check one
- normal
 - abnormal
 - equivocal
- If normal, skip to question 51*

52. Specify results of muscle histochemistry:
check one
 moth-eaten fibers
 cores
 other (*specify abnormality, write pending if results not available*)
-

CONTRACTURE TESTS

53. In your lab, when muscle is exposed to 3% halothane, what is the minimum contracture indicating MH susceptibility?
0. ____ ____ grams
54. To date, how many control patients has this lab evaluated with the 1989 Biopsy Standards protocol? ____ ____ ____ ____

55. MH Diagnostic Muscle Biopsy Results

check one

- positive -- MH susceptible
- negative -- not susceptible to MH
- equivocal -- MH susceptibility not determined
- control biopsy

56. Contracture Test Results

TENSION IN GRAMS MEASURED FROM ZERO OF MEASURING SCALE

HALOTHANE AT 3% (*Required*):

Strip 1

Strip 2

Strip 3

Hours between excision to completion
of test (h).....

— • —

— • —

— • —

Stimulation:

duration (milliseconds).....

—

—

—

frequency (Hz).....

— • —

— • —

— • —

voltage (volts)

— • —

— • —

— • —

current (mA)

— —

— —

— —

Was a length/tension curve done?

check one.....

no

no

no

.....

yes

yes

yes

Pre-drug twitch tension (g).....

— • —

— • —

— • —

(*measure from baseline for twitch tension only*)

Pre-drug tension 3% hal(g).....

— • —

— • —

— • —

Low point tension 3% hal(g).....

— • —

— • —

— • —

Contracture tension developed to 3% hal(g)

— • —

— • —

— • —

Do you consider the tension developed to be
abnormal? *check one*.....

no

no

no

.....

yes

yes

yes

Length (cm).....

— • —

— • —

— • —

Wet Weight (g).....

• — —

• — —

• — —

TENSION IN GRAMS MEASURED FROM ZERO OF
MEASURING SCALE

CAFFEINE ALONE (<i>Required</i>):	<u>Strip 1</u>	<u>Strip 2</u>	<u>Strip 3</u>
Hours between excision to completion of test (h).....	_ . _ _ _	_ . _ _ _	_ . _ _ _
Stimulation:			
duration (milliseconds).....	_ _	_ _	_ _
frequency (Hz).....	_ . _	_ . _	_ . _
voltage (volts)	_ _ . _	_ _ . _	_ _ . _
current (mA)	_ _	_ _	_ _
Was a length/tension curve done? <i>check one</i>	() no	() no	() no
.....	() yes	() yes	() yes
Pre-drug twitch tension (g)..... <i>(measure from baseline for twitch tension only)</i>	_ _ . _ _	_ _ . _ _	_ _ . _ _
Predrug tension 0.5mM (g).....	_ _ . _ _	_ _ . _ _	_ _ . _ _
Plateau tension 0.5mM (g).....	_ _ . _ _	_ _ . _ _	_ _ . _ _
Predrug tension 1.0mM (g).....	_ _ . _ _	_ _ . _ _	_ _ . _ _
Plateau tension 1.0mM (g).....	_ _ . _ _	_ _ . _ _	_ _ . _ _
Predrug tension 2.0mM (g).....	_ _ . _ _	_ _ . _ _	_ _ . _ _
Plateau tension 2.0mM (g).....	_ _ . _ _	_ _ . _ _	_ _ . _ _
Predrug tension 4.0mM (g).....	_ _ . _ _	_ _ . _ _	_ _ . _ _
Plateau tension 4.0mM (g).....	_ _ . _ _	_ _ . _ _	_ _ . _ _
Predrug tension 8.0mM (g).....	_ _ . _ _	_ _ . _ _	_ _ . _ _
Plateau tension 8.0mM (g).....	_ _ . _ _	_ _ . _ _	_ _ . _ _
Predrug tension 32.0mM (g).....	_ _ . _ _	_ _ . _ _	_ _ . _ _
Plateau tension 32.0mM (g).....	_ _ . _ _	_ _ . _ _	_ _ . _ _
CSC (mM).....	_ _ . _ _	_ _ . _ _	_ _ . _ _
% response at 2mM.....	_ _ . _ _	_ _ . _ _	_ _ . _ _
Do you consider the tension developed to be abnormal? <i>check one</i>	() no	() no	() no
.....	() yes	() yes	() yes
If yes, at what concentration?	_ _	_ _	_ _
If yes, at what CSC?	_ _	_ _	_ _
If yes, at what % response?	_ _	_ _	_ _
Length (cm).....	_ . _ _ _	_ . _ _ _	_ . _ _ _
Wet Weight (g).....	. _ _ _	. _ _ _	. _ _ _

TENSION IN GRAMS MEASURED FROM ZERO OF
MEASURING SCALE

HALOTHANE 1% & CAFFEINE (<i>Optional</i>):	<u>Strip 1</u>	<u>Strip 2</u>	<u>Strip 3</u>
Hours between excision to completion of test (h).....	__ . ____	__ . ____	__ . ____
Stimulation:			
duration (milliseconds).....	__	__	__
frequency (Hz).....	__ . __	__ . __	__ . __
voltage (volts)	__ . __	__ . __	__ . __
current (mA)	__	__	__
Was a length/tension curve done? <i>check one</i>	() no	() no	() no
.....	() yes	() yes	() yes
Pre-drug twitch tension (g)..... <i>(measure from baseline for twitch tension only)</i>	__ . ____	__ . ____	__ . ____
Pre-drug tension 1% hal(g).....	__ . ____	__ . ____	__ . ____
Low point tension 1% hal(g).....	__ . ____	__ . ____	__ . ____
Contracture tension developed to 1% hal(g)..	__ . ____	__ . ____	__ . ____
Predrug tension 0.25mM (g).....	__ . ____	__ . ____	__ . ____
Plateau tension 0.25mM (g).....	__ . ____	__ . ____	__ . ____
Predrug tension 0.5mM (g).....	__ . ____	__ . ____	__ . ____
Plateau tension 0.5mM (g).....	__ . ____	__ . ____	__ . ____
Predrug tension 1.0mM (g).....	__ . ____	__ . ____	__ . ____
Plateau tension 1.0mM (g).....	__ . ____	__ . ____	__ . ____
Predrug tension 2.0mM (g).....	__ . ____	__ . ____	__ . ____
Plateau tension 2.0mM (g).....	__ . ____	__ . ____	__ . ____
Predrug tension 4.0mM (g).....	__ . ____	__ . ____	__ . ____
Plateau tension 4.0mM (g).....	__ . ____	__ . ____	__ . ____
Predrug tension 32.0mM (g).....	__ . ____	__ . ____	__ . ____
Plateau tension 32.0mM (g).....	__ . ____	__ . ____	__ . ____
HCSC (mM).....	__ . ____	__ . ____	__ . ____
Do you consider the tension developed to be abnormal? <i>check one</i>	() no	() no	() no
.....	() yes	() yes	() yes
If yes, at what concentration?	__	__	__
If yes, at what HCSC?	__	__	__
Length (cm).....	__ . ____	__ . ____	__ . ____
Wet Weight (g).....	. ____	. ____	. ____

TENSION IN GRAMS MEASURED FROM ZERO OF
MEASURING SCALE

HALOTHANE AT 2% (<i>Optional</i>):	<u>Strip 1</u>	<u>Strip 2</u>	<u>Strip 3</u>
Hours between excision to completion of test (h).....	__ . ____	__ . ____	__ . ____
Stimulation:			
duration (milliseconds).....	__	__	__
frequency (Hz).....	__ . __	__ . __	__ . __
voltage (volts)	__ . __	__ . __	__ . __
current (mA)	__	__	__
Was a length/tension curve done?			
<i>check one</i>	() no	() no	() no
.....	() yes	() yes	() yes
Pre-drug twitch tension (g)..... (<i>measure from baseline for twitch tension only</i>)	__ . ____	__ . ____	__ . ____
Pre-drug tension 2% hal(g).....	__ . ____	__ . ____	__ . ____
Low point tension 2% hal(g).....	__ . ____	__ . ____	__ . ____
Contracture tension developed to 2% hal(g)..	__ . ____	__ . ____	__ . ____
Do you consider the tension developed to be abnormal? <i>check one</i>	() no	() no	() no
.....	() yes	() yes	() yes
Length (cm).....	__ . ____	__ . ____	__ . ____
Wet Weight (g).....	. ____	. ____	. ____

TISSUE AND BLOOD STORAGE

57. Has additional muscle tissue been stored?

check one

() yes

() no

If yes, specify Sample ID No: _____

Location _____

58. Has an additional blood specimen been stored?

check one

() yes

() no

If yes, specify Sample ID No: _____

DNA TESTING

59. Was a genetic exam performed?
check one
 yes unknown
 no

60. Where was the genetic test done?

60a. Is a sample of the DNA stored in the lab?
 yes
 no

61. When was the genetic test done?

62. Which of the RYR1 exons were examined?

If unknown, check here ()

63. Was any mutation associated with MH or central core disease present?
check one
 yes unknown
 no
If yes, specify _____

64. Were any other sequence variants identified?
check one
 yes
 no
If yes, specify _____

COMMENTS ON PATIENT (Optional)

Please mail original to:

The North American Malignant Hyperthermia Registry
UPMC Mercy Hospital
8th Floor, Ermire Building (B)
Room 8522-3
1400 Locust Street
Pittsburgh, PA 15219

MH BIOPSY CENTER CODE NUMBERS

Ottawa Civic Hospital.....	04
Wake Forest University.....	06
Toronto General Hospital	05
University of California at Davis.....	07
UCLA Medical Center.....	08
Uniformed Services University.....	16
University of Minnesota.....	24