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
PATIENT IDENTIFICATION (to be completed by the research subject or subject’s guardian)

1. Name (this is the index research subject)

_______________________  ___________________________ __________________
last  first  middle

2. Previous name

_______________________  ___________________________ __________________
last  first  middle

3. Maiden name: __________________________
last

4. Address

________________________________________________________________________
street address

_______________________  ___________________________ __________________
city  state/province  zip/postal code

____________________
country

5. Phone number

(____) _____ - _______ home
(____) _____ - _______ work

6. E-mail address ____________________________

DEMOGRAPHIC INFORMATION (to be completed by the subject or subject’s guardian)

7. Sex  check one  ( ) male ( ) female
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
   (   ) 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

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

a. name
   ______________________  ______________________  ______________________
   last  first  middle

   Date of birth
Is this the child or the sibling of the 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 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 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 research subject? 
*check one*

( ) child
( ) sibling
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
b. Father of the index research subject

last

Date of father’s birth

year month day

16. Family History Table

Key to Family History table (below)

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

<table>
<thead>
<tr>
<th>Relative's Initials</th>
<th>Registry Number</th>
<th>Relationship to Subject</th>
<th>Sex</th>
<th>Medical Problems</th>
<th>CHCT Test Result</th>
<th>Genetic Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leave blank if relative not registered. Insert &quot;?&quot; if relative registered but number not known.</td>
<td>Select one letter from left-hand column above.</td>
<td>Select one or more numbers from right-hand column above.</td>
<td>Write &quot;pos&quot;, &quot;neg&quot;, &quot;equiv&quot;, &quot;unknown&quot; or &quot;not performed&quot;, &quot;other&quot;.</td>
<td>Specify familial mutation or &quot;neg&quot;, &quot;not performed&quot;, or &quot;other&quot;</td>
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**PHYSICIAN’S IDENTIFICATION** (to be completed by the physician)

Optional-for Registry use only

17. Anesthesiologist’s or other physician’s name

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<table>
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<tbody>
<tr>
<td>last</td>
<td>first</td>
<td>middle</td>
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</table>

18. Hospital name

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19. Hospital Address

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</thead>
<tbody>
<tr>
<td>street address</td>
<td>city</td>
<td>state/province</td>
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20. Physician’s office telephone number (   ) -   -   

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<tbody>
<tr>
<td>country</td>
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</table>

Page
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
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
27. Subjects’s anesthetic history is positive for:
   check all applicable
   ( ) clear-cut clinical MH episode(s)
   ( ) possible MH (not clear-cut MH)
   ( ) masseter muscle rigidity only
   ( ) delayed awakening from general anesthesia
   ( ) positive caffeine halothane contracture test
   ( ) positive calcium uptake test (performed in Boston)
   ( ) other (specify): ________________________________________________
   ( ) none of the above
   ( ) unknown

28a. Date of possible or clear-cut MH episode
   answer for anesthetic most suspect for MH

   _______ __________
   year  month  day

28b. Year of most recent anesthetic (excluding present episode).

    _______ ______
   year
   ( ) unknown

29. Pre-medication and anesthetic agents utilized during possible /clear cut MH:
   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)
   ( ) diphenhydramine (Benedryl)
   ( ) clonidine (Duraclon)
   ( ) ketorolac (Toradol)
   ( ) acetaminophen (Tylenol)
   ( ) diazepam (Valium)
   ( ) lorazepam (Ativan)
   ( ) midazolam (Versed)
   ( ) etomidate (Amidate)
   ( ) ketamine (Ketalar)
   ( ) propofol (Diprivan)
   ( ) alfentanil (Alfenta)
   ( ) fentanyl (Sublimaze)
   ( ) fentanyl and droperidol
   ( ) Innovar
   ( ) meperidine (Demerol)
   ( ) morphine
   ( ) remifentanil (Ultiva)
   ( ) sufentanil (Sufenta)
   ( ) hydromorphone (Dilaudid)
<table>
<thead>
<tr>
<th>Substance</th>
<th>Dose Form</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>unknown</td>
<td></td>
<td></td>
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<tr>
<td>NO potent volatile anesthetics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>sevoflurane (Ultane)</td>
<td></td>
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<tr>
<td>desflurane (Suprane)</td>
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<tr>
<td>isoflurane (Forane)</td>
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<tr>
<td>nitrous oxide</td>
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<tr>
<td>nalbuphine (Nubain)</td>
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<tr>
<td>naloxone (Narcan)</td>
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<tr>
<td>atracurium (Tracrium)</td>
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<tr>
<td>cisatracurium (Nimbex)</td>
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<td>rocuronium (Zemuron)</td>
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<td>vecuronium (Norcuron)</td>
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<td>pancuronium (Pavulon)</td>
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<tr>
<td>other NMB</td>
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<tr>
<td>IM succinylcholine (Anectine)</td>
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<tr>
<td>IV succinylcholine (Anectine)</td>
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<tr>
<td>NO succinylcholine</td>
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<td></td>
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<tr>
<td>edrophonium (Tensilon)</td>
<td></td>
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<tr>
<td>other (specify):</td>
<td></td>
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</tr>
</tbody>
</table>

( ) neostigmine (Prostigmin)
( ) physostigmine (Antilirium)
( ) pyridostigmine (Mestinon)
( ) bupivacaine (Marcaine)
( ) levo-bupivacaine
( ) choroprocaine (Nesacaine)
( ) cocaine
( ) etidocaine (Duranest)
( ) lidocaine (Xylocaine)
( ) mepivacaine (Carbocaine)
( ) prilocaine (Citanest)
( ) procaine (Novocain)
( ) ropivacaine (Naropin)
( ) tetracaine (Pontocaine)
( ) epinephrine
( ) ephedrine
( ) neosynephrine
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
- ____ tachyypnea
- ____ 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:

- ____.____ FiO₂
- ____.____ pH
- ____.____ PCO₂
- ____.____ PO₂
- ____.____ BE (mEq/L) (specify ±)
- ____.____ Bicarbonate (mEq/L)
- ____.____ time (hours after induction)

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)

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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