Participant Profile (form A)

A1.0 - OVERVIEW

Thank you for your time to participate the North American Malignant Hyperthermia Registry (NAMHR) of MHAUS. This Registry consist of 8 survey forms, as below. These forms are to be filled out by NAMHR participants AND their anesthesiologists/health care providers.

- Participant Profile (form A)
- Participant Family Profile (form B)
- Biopsy Report (form C)
- DNA Test Results (form D)
- Clinical Information (form E)
- Before AMRA Episode (form F)
- During AMRA Episode (form G)
- After AMRA Episode (form H)

INSTRUCTIONS to complete the surveys:

1. The first 4 surveys (form A, B, C and D) are to collect information from the participants/patients regarding their history, biopsy information and genetic information; the following 4 surveys (form E, F, G and H) pertain to clinical information about the MH event.

2. Survey forms C can be filled out by either biopsy center staff or by participant's physicians/anesthesiologists; Survey form D can be filled out by either genetic test center staff or by participant's physicians/anesthesiologists.

3. Survey form E is recommended to be filled out by all participants' physicians/anesthesiologists. If a participant has ARMA episode, please also fill out survey forms, F, G and H, in sequence.

4. To register your name with the NAMHR, sign the consent form for release of information by you and your physician to the NAMHR and for release of information by the NAMHR 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 and one for the child.

5. You may need to consult with your anesthesiologist or other physicians responsible for diagnosing you as MH susceptible for assistance.

6. Information sent to the NAMHR will remain confidential.

7. Once the surveys are submitted, all answers are final. Please download the completed form at end of survey for your reference. If you need to make changes, please contact the NAMHR office at

The North American Malignant Hyperthermia Registry of MHAUS
University of Florida
Department of Anesthesiology
Communicore Building
1345 SW Center Drive, Room C2-22
PO Box 100254
Gainesville, FL 32611-0254
(tel: 1-888-274-7899)
REGISTRY INFORMATION

A1.1 - Who will complete this survey?
- Participant (self, parent or guardian)
- Physician
- Anesthesiologist
- Anesthesiologist Assistant (AA)
- CRNA
- Nurse
- Biopsy/DNA Test Center Staff
- NAMHR Administrator
- Other (specify)

A1.1.1 - If other, please specify:

A1.2 - Registry Record Date

A1.3 - Has this case been written up for publication(s) or presented?
- Yes
- No
- I don't know

A1.3.1a - If yes, please specify 1st publication:

A1.3.1b - If yes, please provide the 1st publication link below:

A1.3.2a - If yes, please specify 2nd publication:

A1.3.2b - If yes, please provide the 2nd publication link below:

A1.3.3a - If yes, please provide the 3rd publication link below:

A1.3.3b - If yes, please specify 3rd publication:
## PREVIOUS NAMHR NUMBERS

A2.1 - Did the participant have any previous NAMHR-assigned numbers?  
(If you do not know the previous numbers, please go to the next page)

- Yes
- No

A2.1.1a - AMRA number

A2.1.2b - AMRA Comment

A2.1.2a - AKA number

A2.1.2b - AKA Comment

A2.1.3a - Close relative's report number

A2.1.3b - Close Relative's Report Comment
PARTICIPANT'S PERSONAL INFORMATION

(some of questions are hidden due to lack of properly consent, such as names and birthday, etc.)

A4.1 - Participant First Name
__________________________________

A4.2 - Participant Last Name
__________________________________

A4.3 - Participant Middle Name
__________________________________

A4.4 - Participant Maiden or Prior Last Name
__________________________________

A4.5.1 - Participant's year of birth
(enter year only (e.g. 2017))

A4.5.2 - Participant's month of birth
(enter month only (e.g. 12))

A4.5.3 - Participant's day of birth
(enter day only (e.g. 25))

A4.6.1 - Street Address (line 1)
__________________________________

A4.6.2 - Street Address (line 2)
__________________________________

A4.7 - City
__________________________________
A4.8 - State or Province of Participant's Residence

- Alabama
- Alaska
- American Samoa
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District of Columbia
- Florida
- Georgia
- Guam
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky
- Louisiana
- Maine
- Marshall Islands
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- Missouri
- Montana
- Nebraska
- Nevada
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- North Dakota
- Ohio
- Oklahoma
- Oregon
- Palau
- Pennsylvania
- Puerto Rico
- Rhode Island
- South Carolina
- South Dakota
- Tennessee
- Texas
- Utah
- Vermont
- Virginia
- Washington
- West Virginia
- Wisconsin
- Wyoming
- Alberta
- British Columbia
- Manitoba
- New Brunswick
- Newfoundland and Labrador
- Northwest Territories
- Nova Scotia
- Nunavut
- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan
- Yukon Territory
A4.9 - Zip/Postal Code

A4.10 - Country of Participant's Residence

- USA
- Canada
- Mexico
- Other (specify)

A4.10.1 - If other, please specify:

A4.11 - Home Phone Number

A4.12 - Cell Phone Number

A4.13 - Email Address

A4.14 - Additional information:
PARTICIPANT'S DEMOGRAPHIC INFORMATION

Some of the information contained in this section will be used to make a unique, de-identified code that may be used by investigators via the internet in the NIH/NCATS GRDR? Program, the Global Rare Disease Patient Registry Data Repository.

A5.1 - Age at the clinical encounter

(please enter year in this field, and additional months in the field below (if younger than 1 year old, please enter 0))

A5.1.1 - How many months in addition

(enter months only, e.g. 12)

A5.2 - Sex

- Male
- Female
- Unknown

A5.3 - Pregnancy status at the time of event

- Not pregnant
- Pregnant
- Peripartum - within 24 hours of delivery
- Unknown

A5.4 - Race/Ethnicity

- White
- Hispanic
- Black or African-American
- American Indian/Alaskan Native
- Hawaiian/Pacific Islander
- African
- East Asian
- South Asian
- Middle Asian
- Other (specify)
  (check all applicable)

A5.4.1 - Specify other:

A5.5 - Body Build

- Normal
- Muscular
- Peripartum
- Lean
- Obese
- other (specify)

A5.5.1 - Specify other:

A5.6 - Are you going to enter weight in kilograms or pounds?

- kilograms (kgs)
- pounds (lbs)

A5.6kg1 - Weight in kilograms:

(kgs)

A5.6kg2 - weight equivalent in pounds

(lbs)

A5.6lb1 - Weight in pounds:

(lbs)

A5.6lb2 - weight equivalent in kilograms:

(kgs)
A5.7 - Are you going to enter height in centimeters or feet?

- Height in centimeters:

- Height equivalent in feet:

- Height in feet:

- Additional inches:

- Height equivalent in centimeters:
PARTICIPANT'S MEDICAL HISTORY

A6.1 - Has the participant had 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 (specify how long ago)
☐ recent use of cholesterol lowering drugs (specify drugs and how long ago below)
☐ recent use of antipsychotic drugs (specify drugs and how long ago below)
☐ recent use of serotonin re-uptake inhibitors (specify drugs and how long ago below)
☐ recent use of monoamine oxidase inhibitors (specify drugs and how long ago below)
☐ recent use of illicit drugs (specify drugs and how long ago below)
☐ a regular regimen of strenuous physical activity (specify how long ago below)
☐ intolerance to heat
☐ exercise intolerance due to muscle pain, weakness, or fever
☐ diabetes - Type 1
☐ diabetes - Type 2
☐ more bleeding than expected from minor injuries or surgical procedures
☐ none of the above
☐ other (specify)
☐ unknown

A6.1.1 - If there was a generalized infection, how long ago was it? (days)

A6.1.2 - For Cholesterol drugs - which drugs?

A6.1.3 - For Cholesterol drugs - how long ago was it last ingested? (days)

A6.1.4 - For antipsychotic drugs, which drugs

A6.1.5 - For antipsychotic drugs, how long ago was it last ingested? (days)

A6.1.6 - For serotonin re-uptake inhibitors, which drugs?

A6.1.7 - For serotonin re-uptake inhibitors, how long ago was it last ingested? (days)

A6.1.8 - For monoamine oxidase inhibitors, please specify drugs:

A6.1.9 - For monoamine oxidase inhibitors, how long ago was it last ingested? (days)

A6.1.10 - For illicit drugs, please specify drugs

A6.1.11 - For illicit drugs, how long ago was it last ingested? (days)

A6.1.12 - If a regular regimen of strenuous physical activity, how long ago was the last work-out? (days)

A6.1.13 - If other, please specify:
PARTICIPANT'S FAMILY MEDICAL HISTORY

A7.1 - 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 less than 45 years, but greater than 1.5 years
☐ exercise-associated heatstroke
☐ environmentally induced heatstroke
☐ neuroleptic 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 (myoglobinuria) and muscle pain
☐ myopathy (specify)
☐ idiopathic creatine kinase elevation
☐ diabetes - Type 1
☐ diabetes - Type 2
☐ none of the above
☐ other (specify)
☐ unknown

A7.1.1 - If myopathy, please specify: _________________________________

A7.1.2 - If other, please specify: _________________________________
PARTICIPANT'S PHYSICAL FINDINGS

A8.1 - Has the subject ever had physical findings of:
(check all applicable)

- increased muscle tone
- decreased muscle tone
- generalized muscle weakness
- myopathy (specify type)
- ptosis
- strabismus
- hiatal hernia
- inguinal hernia
- umbilical hernia
- undescended testes
- clubbed foot
- joint hypermobility
- kyphoscoliosis (moderate or severe; curve >45 degrees)
- pectus carinatum
- winged scapulae
- skeletal fractures (e.g. possible osteogenesis imperfect; more than 2)
- gall stones
- kidney stones
- laryngeal papillomas
- none of the above
- other (specify)
- unknown

A8.1.1 - If myopathy, please specify type:
(type 'unknown' if not known)

A8.1.2 - If other, please specify:
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>A9.1 - How many times was this subject anesthetized prior to this case entered?</td>
<td>(please enter an integer)</td>
</tr>
<tr>
<td>A9.2.1 - the year of possible or clear-cut MH episode</td>
<td>(enter year only (e.g. 2017))</td>
</tr>
<tr>
<td>A9.2.2 - the month of possible or clear-cut MH episode</td>
<td>(enter month only (e.g. 12))</td>
</tr>
<tr>
<td>A9.2.3 - the day of possible or clear-cut MH episode</td>
<td>(enter day only (e.g. 25))</td>
</tr>
<tr>
<td>A9.3 - the year of most recent anesthetic (excluding present episode):</td>
<td>(enter year only (e.g. 2017))</td>
</tr>
<tr>
<td>A9.4 - Were unusual metabolic or muscular responses (including myoglobinuria) noted during prior anesthetics?</td>
<td>Yes/No</td>
</tr>
<tr>
<td>A9.5 - Was there unusual delayed awakening from previous general anesthetics?</td>
<td>Yes/No</td>
</tr>
<tr>
<td>A9.6.1 - How many of these prior general anesthetics involved MH triggering agents?</td>
<td>(please enter an integer)</td>
</tr>
<tr>
<td>A9.6.2 - What was/were the triggering agents used?</td>
<td>Isoflurane, Sevoflurane, Desflurane, Halothane, Ether, Methoxyflurane, Succinylcholine</td>
</tr>
<tr>
<td>A9.7a - Indicate the number of inhalational anesthetics without succinylcholine</td>
<td>(This would be any anesthetic that included volatile agents from the list above, but did NOT include succinylcholine)</td>
</tr>
<tr>
<td>A9.7b - Indicate the number of inhalational anesthetics with succinylcholine</td>
<td>(This would be any anesthetic that included volatile agents from the list above and DID include succinylcholine)</td>
</tr>
<tr>
<td>A9.7c - Indicate the number of times succinylcholine without inhalational anesthetics:</td>
<td>(This would be any anesthetic that did NOT include volatile agents from the list above, but DID include succinylcholine)</td>
</tr>
<tr>
<td>A9.8 - How many anesthetics were suspect for possible MH?</td>
<td>(please enter an integer)</td>
</tr>
<tr>
<td>A9.9 - How many fulminant MH episodes occurred?</td>
<td>(please enter an integer)</td>
</tr>
</tbody>
</table>
A9.10 - Past anesthetic history 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)
☐ none of the above
☐ other (specify below)
☐ unknown

A9.10.1 - If other, please specify: ______________________________________