POLICY FOR RELEASE OF DATA
from the North American Malignant Hyperthermia Registry

POLICY FOR REGISTRY DATABASE ACCESS BY INTERNAL RESEARCHERS

Registry Policy

1. An internal researcher is defined as a researcher who is a member of a MH Diagnostic Center, or a Hotline Consultant, Registry Advisory Committee, or MHAUS Board member.

2. An internal researcher from a MH diagnostic center will be permitted access to that portion of the Registry data which exclusively contains data from his or her own MH diagnostic center upon written approval of the researcher's MH diagnostic center director. Data accessed may include names of individual patients who were evaluated by the researcher's MH diagnostic center. It should be noted that these subjects were patients at the respective Biopsy Center. Therefore the Biopsy Center Director at that Center and the staff at that Center provided medical care for the individuals who were enlisted into the Registry from that Center.

3. An internal researcher will be provided with data from the Registry (including data from other MH diagnostic centers) only after meeting the following requirements:
   a) His or her application for research access to the Registry data has been approved by the local Institutional Review Board of that researcher and by the majority of the Registry Advisory Committee.
   b) The researcher has examined a list of Registry tables and fields, and selected specific fields needed in accordance with HIPAA guidelines.

4. Approval of a data access application does not guarantee access to an individual MH biopsy center's patients.

5. The Registry will not reveal the names of patients registered in the Registry to researchers, except as described in item two above.

6. If researchers need to contact individual patients (e.g. to draw blood samples), then the following procedure will be available:
   a) Registry personnel working with the researcher will identify (anonymously to the researcher) patients appropriate for study.
   b) The Registry will notify individual MH biopsy center directors that a researcher would like to obtain specimens from the identified patients.
   c) If the MH biopsy center director wishes to collaborate with the internal researcher, then the Registry will: give the names of the appropriate biopsy center directors to the internal researcher and furnish each biopsy center director with the lists of identified patients.
   d) The NAMHR will contact the patient with information about the study, including contact information for the researcher conducting the study.

7. The internal researcher will NOT reimburse the Registry for costs incurred by the Registry to search the Registry database for appropriate patients or for preparation of a data file. If further costs, such as mailing documents, are incurred, the Registry will charge the internal researcher.

8. Any publications resulting from use of Registry data will cite the North American Malignant Hyperthermia Registry (NAMHR) as a source of the data and document the date the data was extracted from the Registry.

9. The above policies do not apply to staff research projects of the NAMHR.

10. The NAMHR library of papers will be made available to internal researchers upon their request, as allowed by copyright law.