

ANNUAL REPORT for FISCAL YEAR 2014/2015

The Malignant Hyperthermia Association of the United States, or MHAUS
501(c) 3 non-profit organization – Tax ID # 06-1076301
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MHAUS is dedicated to promote optimum care and scientific understanding of Malignant Hyperthermia, a serious and potentially life-threatening hypermetabolic skeletal muscle disorder that could manifest during surgery in genetically susceptible individuals, and other related disorders by improving medical care, providing patients with supportive MH information, improving research related to MH and other heat-related disorders.

Patient safety is our main concern. To assist both healthcare professionals and patients reach a safe outcome from an MH or other heat-related event, or during emergent transfer from one facility to another, MHAUS supports a 24-hour MH Hotline available 365 days every year at **800-644-9737** throughout North America and 001-209-417-3722 outside the U.S. The North American MH Registry of MHAUS is located in Pittsburgh, PA and is the arm of MHAUS that maintains a database of MH-susceptible patients' medical information in a confidential, de-identified electronic database. We also offer the **Neuroleptic Malignant Syndrome Information Service (NMSIS)**, a service of MHAUS designed for psychiatrists who may be dealing with neuroleptic malignant syndrome and need NMS data/clinical resources and access via the website to NMS experts who can help them work through their patient's case to attain the best outcome possible.

Community Economic Impact during Fiscal Year Oct 1, 2014 – September 30, 2015



- Over \$321,000 in salary/benefits, to five individuals
- Over \$104,000 in purchases made from Chenango area businesses and in the surrounding counties in New York State
- Nearly \$13,000 to maintain a building in Sherburne, NY

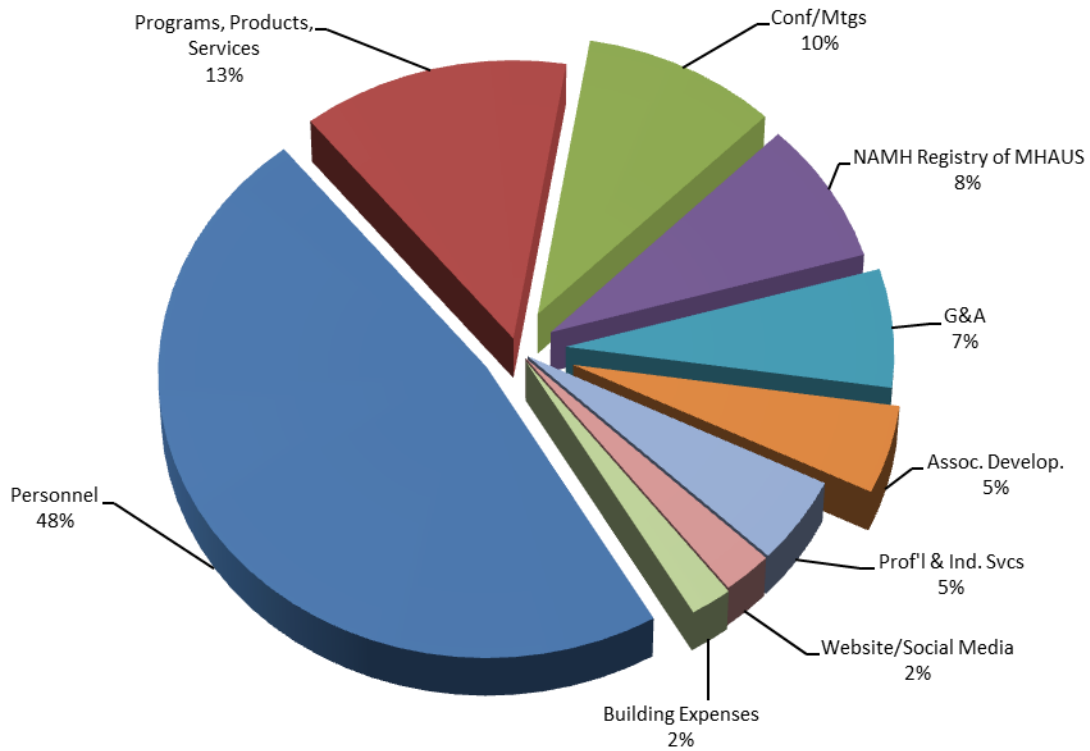
Products/Programs/Services Offered

Educational products and programs to keep healthcare professionals aware of malignant hyperthermia's signs and symptoms to ensure they are prepared and regularly educate themselves on how to react quickly and efficiently in order to save lives. We produce reference literature on malignant hyperthermia and related disorders, share the latest research results via our website in heat-related disorders, and offer products designed for healthcare professionals to use when coordinating their MH preparedness training for this uncommon, but potentially lethal, event. The website offers specific contact forms to ask questions directly of MH experts, internal hierarchy and staff within MHAUS and a process is in place with a goal of answers in 72 hours or less. It also offers video clips as resources regarding muscle biopsy testing and historical references and research, as well as links to other companies and organizations we consider to be additional resources in related areas of interest.

Accomplishments in Fiscal Year 2014-2015

- *MH Prep Checks* continue to be popular; several more were completed during the year, including one in Anchorage, Alaska. The feedback from all the MH Prep Check program continues to be very positive from the facility staff and the MH expert. The facility staff meet the MH expert who would be on the other end of an MH Hotline call during an MH event who brings reality to the need for immediate reaction as they assume the hotline consultant role. The positive result is immeasurable. The experts provide feedback, quality improvement suggestions, and oversight of placement of MH cart and supplies to assure MH preparedness of staff and the overall facility. Should a transfer be needed, they review the plan of action to transfer the patient and/or oversee the actual transfer to verify the hand off of the patient is seamless and correct. This program cannot be found elsewhere and the resulting experience is exemplary.
- Historically relevant video placed on MHAUS website depicting the late 1970s/early 1980s "pig video" from Dr. Thomas J. J. Blanck's archives depicting an actual MH event and reversal, reasoning for the muscle biopsy testing to verify malignant hyperthermia susceptibility, and an MH simulation to highlight the realistic picture of all the things that must be accomplished simultaneously when an MH event occurs.
- Hired a Projects Coordinator to oversee MHAUS website's social media development, handle increasing number of MH Prep Checks, develop new and creative ideas for MH educational product and avenues to broaden MHAUS exposure in the immediate community and worldwide.
- Provided MH expert speakers at multiple meetings across North America; e.g., *Washington State Council of Perioperative Nurses* (Dr. Greg Allen), *Wisconsin Society of PeriAnesthesia Nurses* (Dr. Cynthia Wong), *Operating Room Nurses Association of Canada (ORNAC)* and *Sunnybrook Health Sciences Centre in Canada* (Dr. Sheila Riazi)
- The newest version of the MH Operating Room Protocol Poster was placed on the Canadian website by Dr. Sheila Riazi to promote its use there.
- MH presentation coordinated by an MH Expert, Dr. Kumar Belani, in India in the Spring of 2015.
- *American Society of PeriAnesthesia Nurses (ASPAN)* designated an MHAUS liaison to foster a more direct link between our two organizations.
- MHAUS representatives participated in a meeting by the *Korey Stringer Institute* and the *National Athletic Trainers Association* to discuss possible relationship between heatstroke and malignant hyperthermia. It is hoped that more joint efforts will be forthcoming to address this issue and provide helpful resources.
- Major coordination of revisions to MHAUS MH educational materials and the MHAUS website resources to include the newest products for MH available on the market, Ryanodex® (another option for dantrolene sodium for injection) and VaporClean Filters.
- Development began of Knowledge Bank within the MHAUS website to better facilitate answers and resources to customers' questions about the management, recognition, heat-related disorders, and other MH-related questions from healthcare providers and MH-susceptibles and their families.
- *North American MH Registry of MHAUS* developed an online RSR form for ease of completion and submission by patients interested in placing their MH-susceptible information in the database for research and personal family access. This can be obtained by contacting the Registry at 888-274-7899 for the link. Many of the MH experts publish research on a regular basis in prestigious journals; a recent list can be found in the bibliography of publications from the NAMH Registry at the following url: <http://www.mhaus.org/registry/research/publications>.

Breakdown of Expenses October 1, 2014 through September 30, 2015



MHAUS Staff as of December 2015 – Who to call?

Dianne Daugherty, Executive Director
 Gloria Artist, MH Hotline Coordinator
 Fay Kovack, Fulfillment Coordinator [orders, customer support]
 Sara Prosser, Administrative Assistant
 Tina Roalef, Projects Coordinator

2014-2015 Board of Directors

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MH Hotline Medical Director

Ronald S. Litman, DO

North American MH Registry of MHAUS Director

Barbara W. Bandom, MD

FY 2014-2015 Statement of Expenses (rounded)

Personnel & General and Administration	345,050
Programs, Products, Services	84,493
Conferences/Meetings	61,763
North American MH Registry of MHAUS	50,969
Association Development	31,331
Professional & Independent Services	30,637
Website/Social Media	15,404
Building Expenses	12,896