

ANNUAL REPORT for FISCAL YEAR 2015/2016

The Malignant Hyperthermia Association of the United States (MHAUS)
501(c) 3 Non-profit Organization – Tax ID # 06-1076301
1 North Main Street, P. O. Box 1069, Sherburne, NY 13460 www.mhaus.org
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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 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, 2015 – September 30, 2016

- Over \$325,000 in salary/benefits, to six individuals
- Over \$114,000 in purchases made from Chenango area businesses and in the surrounding counties in New York State
- Over \$13,000 to maintain a cornerstone building in Sherburne, NY

Products/Programs/Services Offered

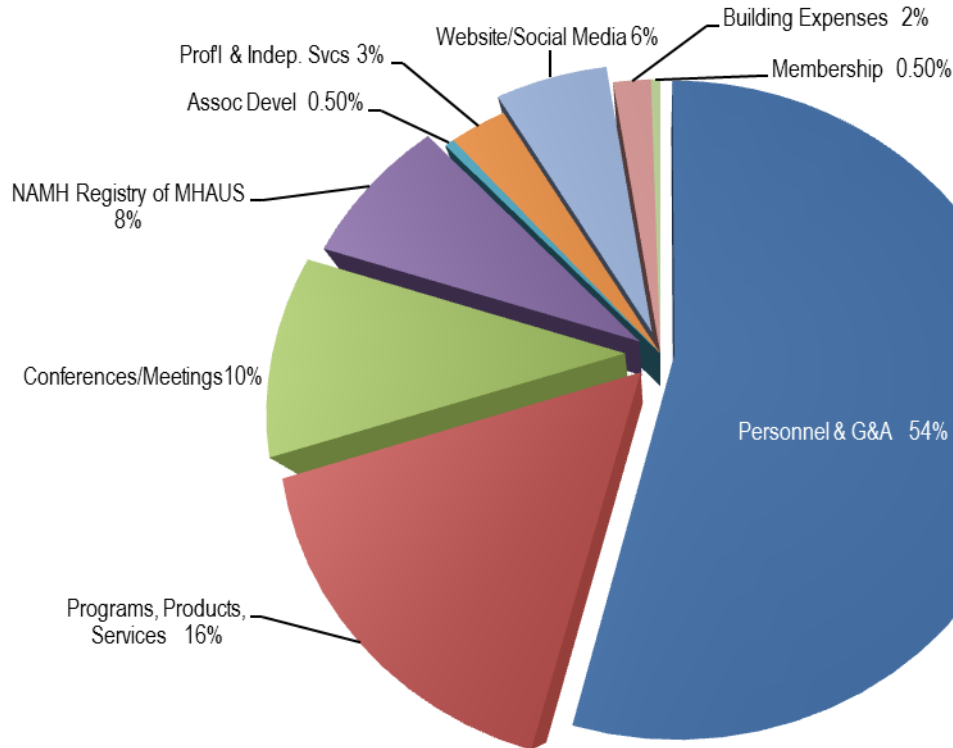
Educational products and programs to keep healthcare professionals aware of malignant hyperthermia's signs and symptoms to ensure they are prepared and regularly educate themselves on how to react quickly and efficiently in order to save lives. We produce reference material on malignant hyperthermia and related disorders, share the latest research results 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 contact forms to ask questions of MH experts, internal hierarchy and staff with a goal to provide answers in 72 hours or less. We provide video clips to enrich specific answers to frequently asked questions, and to provide recent and historical references and research. We share links to other companies and organizations who share related areas of interest; developed prominently displayed visuals on the home page encompassing all types of product updates/resources for information seekers.

Accomplishments in Fiscal Year 2015-2016

- *MH Prep Checks* continue to be popular with 12 completed this past year. This program cannot be found elsewhere and the resulting feedback on the overall experience was that the program is exemplary.
- Relevant information was added to the MHAUS website in a new medium; short (45 seconds or so) video clips of one of the MH experts answering the regularly asked questions are available to enhance the learning experience online. More to come in the near future.
- Historical information is on the MHAUS website, e.g., an interview of Dr. Thomas Nelson, a well-known MH researcher who did much work with the MH-susceptible pigs and was instrumental in developing the "gold standard" caffeine-halothane contracture test (CHCT).
- Social Media increased the impact MHAUS made on our community in a big way. The level of engagement is increasing in a positive direction and plans are in process to further enhance the visitor's engagement by sharing more bits of information and periodic challenges to visitors.
- Prior to August 2016, MHAUS was faced with an unforeseen challenge of finding a new home for the *North American MH Registry of MHAUS*. A temporary home was found through the gracious management of the University of Pittsburgh Department of Nurse Anesthesia to continue the functioning of the Registry while promotion of Request for Proposals was instituted. The final location will be determined by the board of directors in 2017.
- It was determined it was time to hold another Scientific Conference in 2017 and plans were begun to find a location and program.
- Support was maintained from the major manufacturers of the antidote for malignant hyperthermia, other industry, and our members.
- The first annual *MH Memorial Ride* was held in August in Sherburne, NY and was enjoyed by all as a fun-filled, family-oriented event.
- Hotline Consultant-Professional Advisory Council meeting was held in Chicago in mid-September with good attendance and comprehensive communication on topics of interest to clinicians and patients alike.
- Anesthesia Residents Group began involving up and coming anesthesiologists who have an interest in MH. Their first accomplishment was to rewrite clinical articles that patients asked be redacted to a level that would better communicate with the layperson. They completed multiple articles and will complete more in the months and years to come.



Breakdown of Expenses October 1, 2015 through September 30, 2016



MHAUS Staff as of December 2016 – Who to call?

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

2015-2016 Board of Directors

President: Henry Rosenberg, MD, CPE
Vice President: Bonnie Denholm, DNP, RN, CNOR
Vice President – Scientific Development: Ronald S. Litman, DO
Vice President – Director, NMSIS: Stanley Caroff, MD
Secretary: Steven Napolitano, Esquire
Treasurer: Joseph Tobin, MD

Board Members

Curt Keller
 Kathleen Keller
 Debra Merritt, CRNA, MSN
 Sheila Muldoon, MD
 Sheila Riazzi, MSc, MD, FRCPC
 Nicholas Silvestri, MD
 Georgirene Vladutiu, PhD

Professional Advisory Council Chair

Robert T. Dirksen, PhD

MH Hotline Medical Director

Ronald S. Litman, DO

North American MH Registry of MHAUS Director

Barbara W. Bandom, MD

FY 2015-2016 Statement of Expenses (rounded)

Personnel & General and Administration	379,038
Programs, Products, Services	110,392
Conferences/Meetings	70,380
North American MH Registry of MHAUS	52,000
Association Development	3,235
Professional & Independent Services	22,370
Website/Social Media	38,799
Building Expenses	13,181
Membership	3,590