

2015 ANNUAL REPORT

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 during an unforeseen MH event or during emergent transfer from one facility to another due to MH or another heat-related event, 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. Another service of MHAUS is the North American MH **Registry** of MHAUS located in Pittsburgh, PA. The Registry 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 in their patient and need NMS data and clinical resources as well as 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, 2013 – September 30, 2014



- **Over \$344,000** in salary/benefits, to six individuals
- **Over \$139,150** in purchases made from Chenango area businesses and in the surrounding counties in New York State
- **Invested over \$ 12,000** to maintain a building in Sherburne, NY

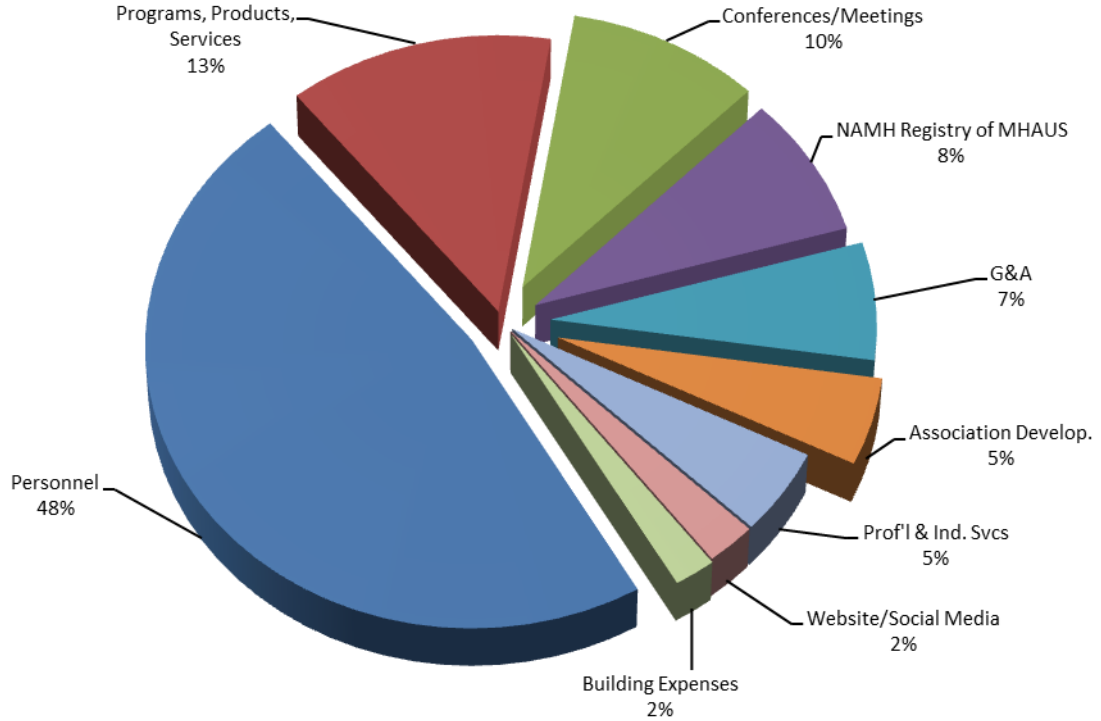
Products/Programs/Services Offered

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. Our website offers video clips as resources regarding muscle biopsy testing as well as links to other companies and organizations we consider to be additional resources in related areas of interest.

Accomplishments in Fiscal Year 2013-2014

- Partner Membership with the *Association of Operating Room Nurses (AORN)* put into place to make MHAUS membership available to active AORN members at a reduced cost.
- Partner Memberships developed with the *American Association of Nurse Anesthetists (AANA)* and the *Society for Ambulatory Anesthesia (SAMBA)*
- Hired a Membership Coordinator to develop ongoing communication and updates with members, past and present, and to develop programs and strategies to share solid reasons for MHAUS membership. This position was active for 5 months and began important strides forward.
- *A Roadmap to MH Answers* completed and placed online and in limited printed format to address a patient's concerns when diagnosed with malignant hyperthermia. Offers answers to questions about what this means to them and their family, testing options, and offers genetic and insurance resources.
- MH Hotline Medical Director instituted database using *RedCap* and developing process to input hotline calls into data in timely manner.
- Held Scientific Conference, November 2013, in Toronto, Ontario, Canada at Dr. Sheila Riazi's facility. Offered CME credits to the 70+ attendees and brought in RYR-1 experts from across the continent and internationally. Dr. Riazi wrote synopsis for peer-reviewed publication.
- First *MH Prep Check* held in Sioux City, Iowa in March 2014 with Dr. Mo Shukry as on-site MH expert. Several more in planning stages for upcoming fiscal year.
- Historically relevant video of Dr. Gerald Gronert and Dr. Henry Rosenberg completed covering their recollections of the development of MH research and MHAUS growth over 30+ years.
- Dr. Keith Ellis videotaped interview completed relaying rich content with regard to the decisions made by scientists and corporate management toward the pursuit of development of the antidote, dantrolene sodium for injection. The insights gained were shared via multiple video clips on the MHAUS website for posterity.
- MH Mini-conference held in Rochester, NY which was a resounding success.
- MH Hotline Consultants, Professional Advisory Council, and Board members met in Chicago in September 2014 for a day-and-a-half meeting to discuss various topics of concern and to review MHAUS recommendations as well as consider strategy for the future.
- Robert Dirksen, PhD, appointed Chair of the Professional Advisory Council.
- Sheila Riazi, MSc, MD, FRCPC, Director of Toronto MH Investigation Unit, appointed to MHAUS Board of Directors
- Curt and Kathleen Keller, MH-susceptible family members, appointed to MHAUS Board of Directors.

Breakdown of Expenses October 1, 2013 through September 30, 2014



MHAUS Staff as of December 2014 – Who to call?

Dianne Daugherty, Executive Director
 Gloria Artist, MH Hotline Coordinator
 Fay Kovack, Fulfillment Coordinator [orders, customer support]
 Sara Prosser, Administrative Assistant
 Michael Wesolowski, Development Coordinator

2013-2014 Board of Directors

President: Henry Rosenberg, MD, CPE
Vice President: Bonnie Denholm, MS, BSN, RN, CNOR
Vice President – Scientific Development: Sheila Muldoon, MD
Vice President – Director, NMSIS: Stanley Caroff, MD
Secretary: Steven Napolitano, Esquire
Treasurer: Joseph Tobin, MD
Board Members
 Curt Keller
 Kathleen Keller
 Ronald Litman, DO
 Debra Merritt, CRNA, MSN
 Sheila Riazi, MSc, MD, FRCPC
 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 2013-2014 Statement of Expenses (rounded)

Personnel & General and Administration	344,037
Programs, Products, Services	114,000
North American MH Registry of MHAUS	65,390
Conferences/Meetings	45,413
Professional & Independent Services	34,634
Public Relations/Website	18,710
Association Development	17,070
Building Expenses	12,042
TOTAL	651,297