

ANNUAL REPORT for FISCAL YEAR 2016/2017

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
Tel: 607-674-7901 Fax: 607-674-7910

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 remains 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, 2016 – September 30, 2017

- Over \$391,000 in salary/benefits, to six individuals
- Nearly \$72,000 in purchases made from Chenango area businesses and in the surrounding counties in New York State
- Nearly \$14,000 to maintain a cornerstone building in Sherburne, NY



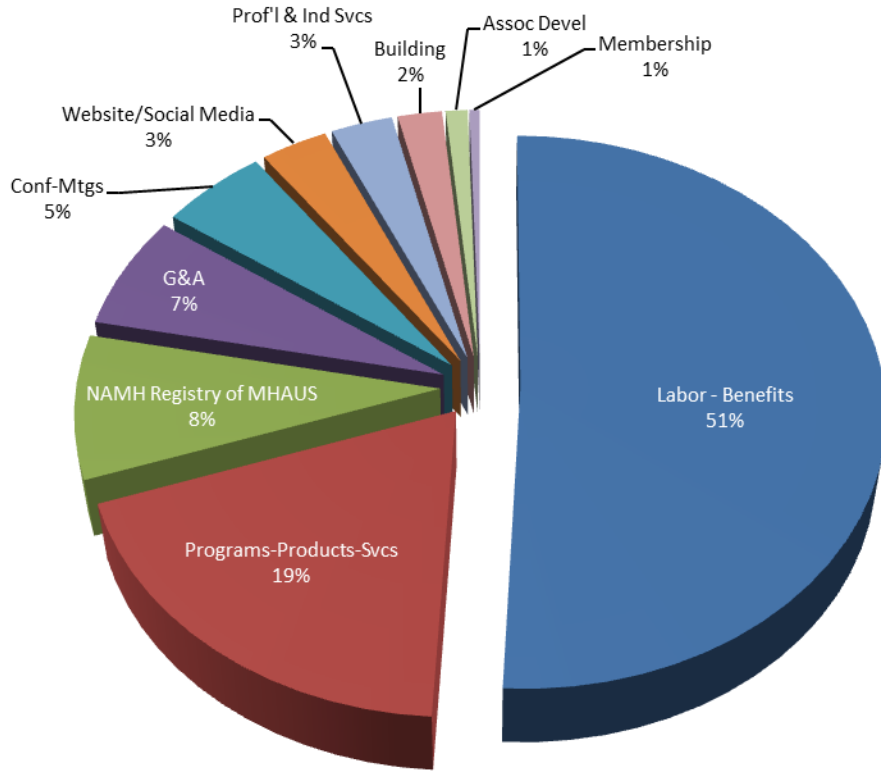
Products/Programs/Services Offered

MHAUS provides 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 materials are reviewed/revised every 2-3 years in order to assure they are up-to-date and relevant to our customers' needs. The website offers contact forms for all types of questions and provides answers in 72 hours or less. We develop video clips to augment the answers to frequently asked questions, share references, research and recommendations that are vetted throughout the organization and externally. We share links to other companies and organizations with products relevant to our customers, develop prominent visuals and engaging articles and questions for our visitors via Facebook and Twitter regularly on the website's home page.

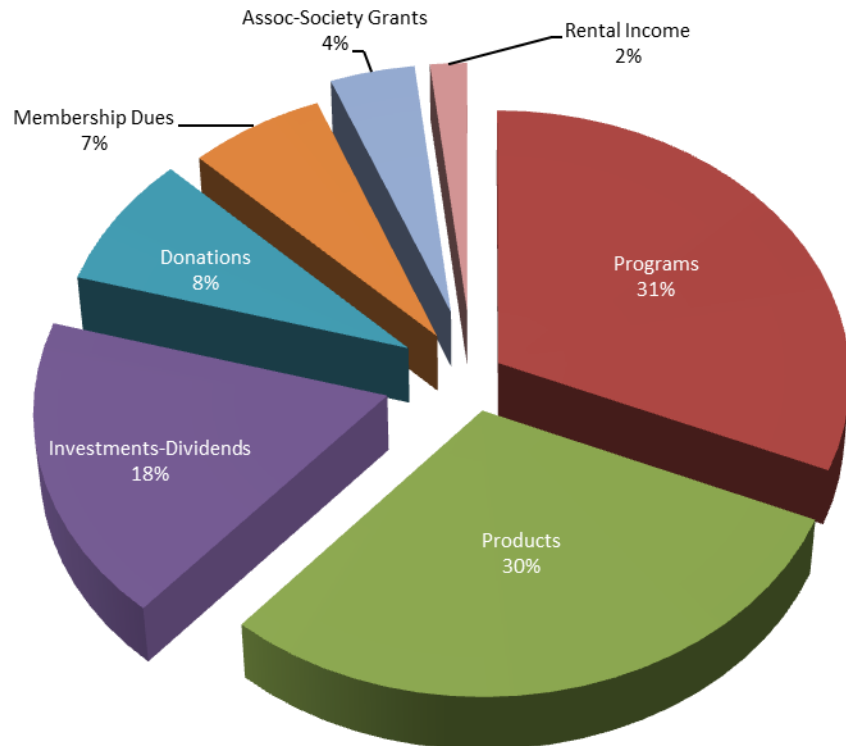
Accomplishments in Fiscal Year 2016-2017

- Historical interviews have been added to the MHAUS website, i.e., Dr. Michael Denborough, one of the pioneers of malignant hyperthermia awareness; interviews with long-standing MH experts Drs. Sheila Muldoon and Henry Rosenberg.
- Social Media continues to be at the forefront of MHAUS' engagement with our customer base. We are regularly updating our Facebook and Twitter accounts and encouraging communication and feedback from website visitors.
- Online webinars designed specifically for healthcare professionals and patients were provided. They ranged from a webinar only for regulatory agency surveyors to deliver current MHAUS recommendations and the reasoning behind them, to a webinar for patients' participation, allowing for questions to our MH experts – all designed to achieve a better understanding of the MH disorder and its genetic inheritance. All were well received, reinforcing our decision to continue to provide them in the future.
- The *North American MH Registry of MHAUS* (Registry) move from the *University of Pittsburgh* to the *University of Florida-Gainesville* was a major undertaking. The University of Pittsburgh was very supportive throughout the search activity. The RFP process brought a number of likely candidates, but the final decision made after much deliberation and conversations with the facilities, was to relocate to Florida. We anticipate great forward momentum from within the new location; the support from all staff involved and the University of Florida is exemplary.
- The MHAUS Board of Directors is evolving in order to include additional clinical expertise. For instance, we have added a member of the *American Society of PeriAnesthesia Nurses* (ASPAN). We continue to search for pharmacy, emergency room healthcare professionals, neurologists and heat stroke expert candidates for board membership for their invaluable acumen.
- The Scientific Conference was held in Minneapolis, MN at the University of Minnesota in September 2017. Presentations were well received by the audience; patients attended the event to share their feedback to the research community, as well as learn from them.
- Support from major manufacturers of the malignant hyperthermia antidote, although reduced, is appreciated. The MHAUS membership dues, donations, dedicated family support, and other industry support continue to sustain the organization.
- The second annual *MH Memorial Ride* was held August 2017 in Sherburne, NY and seems to be slowly growing in participation.

Breakdown of MHAUS Expenses October 1, 2016 through September 30, 2017



Breakdown of MHAUS Income October 1, 2016 through September 30, 2017



MHAUS Board, Staff and Financial Summary Page

2016-2017 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

Georgirene Vladutiu, PhD

Stacey Watt, MD

Professional Advisory Council Chair

Robert T. Dirksen, PhD

MH Hotline Medical Director

Ronald S. Litman, DO

North American MH Registry of MHAUS Director

Barbara Brandom, MD

MHAUS Staff as of December 2017

Dianne Daugherty, Executive Director

Gloria Artist, MH Hotline Coordinator

Fay Kovack, Fulfillment Coordinator

Sara Prosser, Administrative Assistant

Tina Roalef, Projects Coordinator

FY 2016-2017 Statement of Expenses (rounded)

Personnel & General and Administration	372,440
Programs, Products, Services	122,288
North American MH Registry of MHAUS	54,487
Conferences/Meetings	33,643
Website/Social Media	21,185
Professional & Independent Services	19,488
Building Expenses	13,956
Association Development	6,873
Membership	3,217