

ANNUAL REPORT for FISCAL YEAR 2018/2019
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 elsewhere. 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, 2018 – September 30, 2019

- Nearly \$315,000 in salary/benefits to four individuals
- Over \$60,000 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



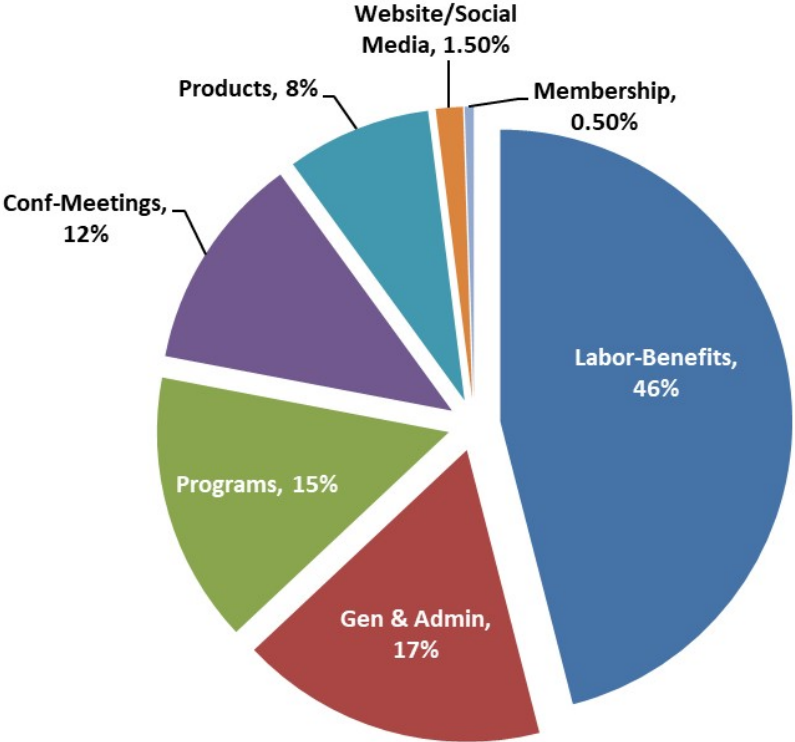
MHAUS provides educational products and programs to keep healthcare professionals aware of malignant hyperthermia's signs and symptoms to ensure they are prepared and regularly educate themselves on how to react quickly and efficiently in order to save lives. We produce reference material on malignant hyperthermia and related disorders, share the latest research results on 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 provide video clips to augment the answers to frequently asked questions, share references, research and recommendations that are vetted internally 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. Monthly online webinars designed for healthcare professionals and patients on a rotating basis. They have been very well received and are free to MHAUS members.



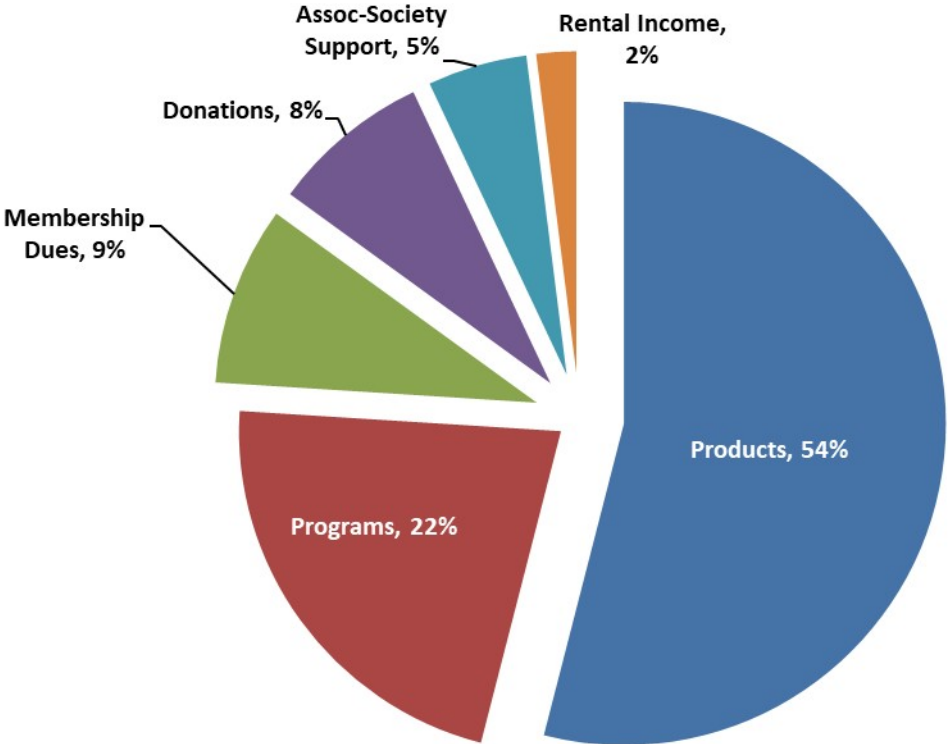
Accomplishments in Fiscal Year 2018-2019

- Online webinars designed specifically for healthcare professionals and patients continue to grow in popularity. The percentage of registrations is increasing as is the final percentage of those who actually attend the webinar.
- We began a concerted effort to communicate with various genetic testing companies to develop relationships that will allow for further clarification of the genetic testing possibilities available to patients who want to better understand the implications/choices.
- A joint meeting of the MH Hotline Consultants and Professional Advisory Council members was held in September in Chicago to discuss any concerning issues with the MH Hotline process and to share hotline data results. Dr. Teeda Pinyavat has taken on the role of Director of the MH Hotline and is focused on quality improvements to the overall process.
- The MH Mock Drill Kit was revised to bring it up-to-date and now includes 3 separate MH simulations, including a scenario where the outcome is not positive, with disastrous results from the medical team not being prepared for MH.
- To assure we remain compliant with governmental regulations regarding charitable organizations, MHAUS has retained a company to manage the very involved and intricate process of maintaining yearly state charitable registration requirements.
- The MHAUS Board is in the process of adding a genetic counselor, a heatstroke expert, and a new AORN representative to board membership in order to attain/continue access to invaluable feedback and insight.
- Support from major manufacturers of the malignant hyperthermia antidote is appreciated. The MHAUS membership dues, donations, dedicated family support, and other industry support continue to sustain the organization.
- The board spent much effort this past year reviewing by-laws, strategic plan, corporate documents, risk assessment and succession planning in order to assure the organization is prepared for the future with a solid plan and staff in place. As a result, specific committees are developing to allow board involvement in fundraising activities, education development, scientific (research and genetics) advances, the North American MH Registry of MHAUS evolution, and board development. Efforts to assure a smooth transition within the board and staff positions will continue to be a focus into the future in order to remain resilient and relevant.

Breakdown of MHAUS Expenses October 1, 2018 through September 30, 2019



Breakdown of MHAUS Income October 1, 2018 through September 30, 2019



MHAUS Board, Staff and Financial Summary Page

2018-2019 Board of Directors

President: Henry Rosenberg, MD, CPE

Vice President: Bonnie Denholm, DNP, RN, CNOR

Vice President – Director, NMSIS: Stanley Caroff, MD

Secretary: Steven Napolitano, Esquire

Treasurer: Joseph Tobin, MD

Board Members

Curt Keller

Darlene Mashman, MD

Cheryl Mercer

Terri Passig, BSN, RN, CPAN, CAPA CCRN

Sheila Riazzi, MSc, MD, FRCPC

Jacqueline Sumanis, DNAP, CRNA

Georgirene Vladutiu, PhD

Stacey Watt, MD

Professional Advisory Council Chair

Robert T. Dirksen, PhD

MH Hotline Medical Director

Teeda Pinyavat, MD

North American MH Registry of MHAUS Director

Nikolaus Gravenstein, MD

MHAUS Staff as of December 2019

Dianne Daugherty, Executive Director

Gloria Artist, MH Hotline Coordinator

Fay Kovack, Fulfillment Coordinator

Tina Roalef, Projects Coordinator

FY 2018-2019 Statement of Expenses (rounded)

Labor & Benefits	314,972
General & Administration	114,817
Programs	104,942
Products	58,050
Conferences - Meetings	82,946
Website/Social Media	10,555
Membership	3,388

Does not include all expenses.

Various miscellaneous expenses not tallied