

## ANNUAL REPORT for FISCAL YEAR 2019/2020

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](http://www.mhaus.org)  
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MHAUS is dedicated to promote optimum care and scientific understanding of Malignant Hyperthermia (MH), 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/year, handling ~600 calls/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 searchable database of MH-susceptible patients' medical information in a confidential, de-identified manner. We offer the **Neuroleptic Malignant Syndrome Information Service (NMSIS)**, a service of MHAUS designed for psychiatrists dealing with neuroleptic malignant syndrome and need NMS data/clinical resources and website access to NMS experts who can help them work through their patient's case to attain the best outcome possible. Board/staff succession planning and internal board development was a primary focus area.

### Community Economic Impact during Fiscal Year Oct 1, 2019 – September 30, 2020

- Nearly \$318,000 in salary/benefits to four individuals
- Nearly \$57,000 in purchases made from Chenango area businesses and in the surrounding counties in New York State
- Nearly \$9,000 to maintain a cornerstone building in Sherburne, NY

### Products/Programs/Services Offered

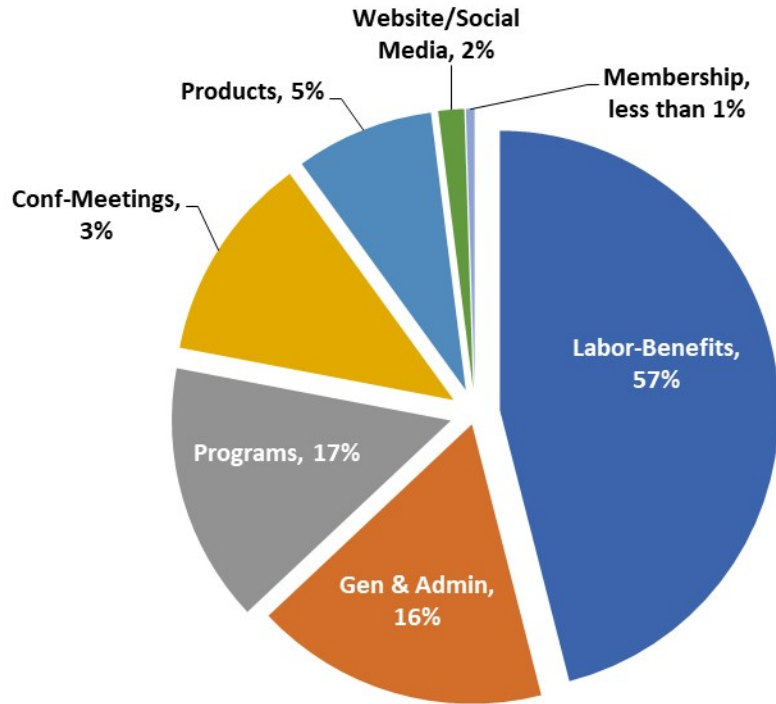
MHAUS provides educational products, programs and publications to keep healthcare professionals aware of malignant hyperthermia's signs and symptoms to regularly educate themselves to react quickly and efficiently. We produce reference material on malignant hyperthermia and related disorders, share MH research results, including collaborative efforts to delineate genetic changes that predispose to MH, and offer products designed for healthcare professionals to use when coordinating their MH preparedness training for this potentially lethal event. The materials are reviewed/revised every 2-3 years by MH experts 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 furnish video clips to augment answers, share references, research, and recommendations vetted internally and externally. Links for products relevant to our customers' needs are offered to other companies and organizations. Prominent visuals and engaging articles and questions are shared with visitors via Facebook and Twitter on the website's home page. Monthly online webinars designed for healthcare professionals and patients now have CME credits available.



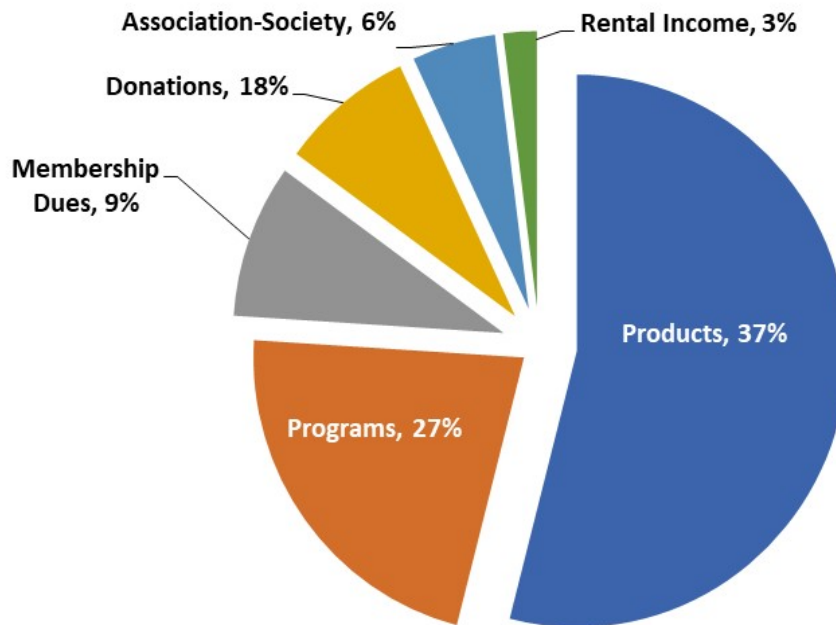
### Accomplishments in Fiscal Year 2019-2020

- The MHAUS organization was negatively impacted along with many others by the 2020 COVID Pandemic. The slow to stagnant economy had a direct impact on the anticipated revenue and continual adjustments were made to meet the challenge of ongoing expenses to be paid with income levels that dropped drastically from previous years. Through prudent expense management wherever possible, the foresight to implement a savings plan for just such an unforeseen event, and the application and receipt of a PPP loan to pay staff, we survived.
- Free online webinars for MHAUS members, designed specifically for healthcare professionals and patients, now provide CME credits to those who want them. MHAUS members can obtain the credits at a 30% discount.
- New board members during the year include Megan Betts, a genetic counselor, and Julie Cahn, AORN representative.
- We began work with a virtual reality company to possibly provide MH Mock Drills via this medium as a joint venture.
- Support from major manufacturers of the malignant hyperthermia antidote is very appreciated. The MHAUS membership dues, donations, dedicated family support, and other industry support continues to help sustain the organization.
- The board focused on elements within the organization through increased board member involvement as chair and/or members of specific committees focused on fundraising, research, education, etc. It is hoped this change will bring about more interaction between board members and staff to ensure steady forward progress.
- Monumental efforts by MHAUS staff, the MH Registry of MHAUS staff at the University of Florida (UFL), the MH Hotline Medical Director, Dr. Pinyavat, and many others resulted in the transition of MH Hotline data from Children's Hospital in Philadelphia, PA to UFL; including new surveys to obtain follow up information from the caller and MH Hotline Consultant. It is hoped the hotline data can be merged into the Registry's database in the future to enhance research efforts.
- MH Incidence Study Request for Proposals advertised and grant winner chosen. Work has begun this fiscal year.

**Breakdown of MHAUS Expenses October 1, 2019 through September 30, 2020**



**Breakdown of MHAUS Income October 1, 2019 through September 30, 2020**



## MHAUS Board, Staff and Financial Summary Page

### 2019-2020 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

Megan Betts, MS. LGC

Julie Cahn, DNP, RN, DNOR, RN-BC, ACNS-BC, CNS-CP

Curt Keller

Darlene Mashman, MD

Cheryl Mercer

Terri Passig, BSN, RN, CPAN, CAPA CCRN

Sheila Riazi, MSc, MD, FRCPC

Jacqueline Sumanis, DNAP, CRNA

Georgirene Vladutiu, PhD

Stacey Watt, MD

### Professional Advisory Council Chair

Sheila Riazi, MSc, MD, FRCPC

### MH Hotline Medical Director

Teeda Pinyavat, MD

### North American MH Registry of MHAUS Director

Nikolaus Gravenstein, MD

### Registry Manager

Amy M. Gunnett, RN, CCRC

### MHAUS Staff as of December 2020

Dianne Daugherty, Executive Director

Gloria Artist, MH Hotline Coordinator

Fay Viera, Fulfillment Coordinator

Tina Roalef, Projects Coordinator

### FY 2019-2020 Statement of Expenses (rounded)

Labor & Benefits	317,692
General & Administration	86,511
Programs	91,402
Products	28,359
Conferences - Meetings	13,312
Website/Social Media	11,34
Membership	3,347

***Does not include all expenses.***

*Various miscellaneous expenses not tallied*