

ANNUAL REPORT

The Malignant Hyperthermia Association of the United States, or MHAUS,
a 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 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**, 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 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, 2011 – September 30, 2012

- **Nearly \$460,000** in salary/benefits, to six individuals and payments to outside contractors residing in the area
- **Over \$92,000** in purchases made from Chenango area businesses and in the surrounding counties
- **Paid over \$300** in taxes to New York State Department of Taxation for products sold in New York counties
- **Invested over \$17,000** in maintaining a building in Sherburne, NY

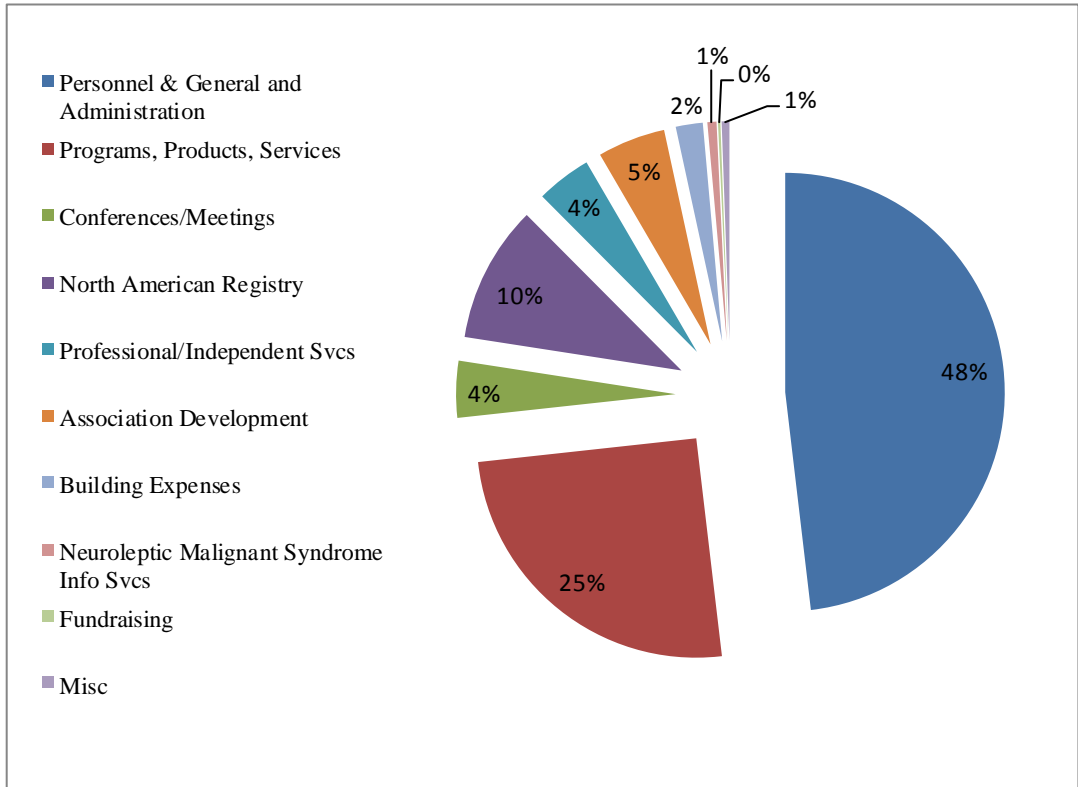
Products/Programs/Services Offered

Educational products and programs to keep healthcare professionals aware of malignant hyperthermia's signs and symptoms to ensure they are prepared for it 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. We share videoclips on our website to share specific information about the muscle biopsy test to determine MH susceptibility and offer links to other companies and organizations who share our interests and offer additional resources.

Accomplishments in Fiscal Year 2011-2012

- We added a new MH Hotline Consultant to the group to assist callers dealing with an MH emergency.
- Celebrated the **30th anniversary of the MH Hotline** and recognized the current MH Hotline Consultants at the American Society of Anesthesiologists (ASA) meeting in October.
- Added a **Development Officer** to staff at the same time our Scientific Officer resigned to take another position.
- Held official **Open House** in August 2012 to share building upgrades/changes made with the community. MHAUS President, Dr. Rosenberg and board member, Michael Paino, were in attendance.
- Coordinated effort with **CMEZone** now offers an online MH educational program, with CEU credits, as of December 2011. Thousands of visitors, **primarily nurses**, have taken advantage of this item; it continues to be popular.
- The MH Hotline management was moved to *MedicAlert* in August 2012. This partnership included moving the *MHAUS MH ID Tag* program as well, into their well-known ID Tag system and online support. This move brings us back full circle to where it was initially managed in the 1980s.
- An **MH Mini-conference** was held the Milwaukee, Wisconsin area at the medical facility of one of our board members, Jenny Geurts and a hotspot for MH susceptible families. The attendance was solid and question and answer period enlightening.
- The **Emergent Transfer Plan and Checklist** for office-based facilities was completed and the resulting products are available for assisting office-based facilities prepare for an unforeseen MH event and transfer. This was another joint effort between MHAUS and the Society for Ambulatory Anesthesia (SAMBAA) to offer a tool that had been requested by customers in those facilities and recognized as important by both groups.
- MHAUS website integrated an online association management software package to allow visitors to become members or friends, make changes to their personal profile, join online groups, become active in supporting the MHAUS mission, easily purchase products or donate to MHAUS, and more.
- "Freshness Policy" now associated with printed materials to assure the last **revision date** is portrayed and scheduled reviews are on track and consistent.
- We completed the revision and reformatting of the **MH In-service to a DVD** format with chapter layout and easy transition from each chapter or to review a specific topic repeatedly. Containing videoclips and graphics to share important MH information. We added an online test on the content and, in addition, allow those taking the test to post their attention to MH preparedness training on the MHAUS website upon successful completion of the test. In this way, patients who are looking for MH prepared staff to handle possible upcoming surgery, will have this additional resource to make a decision.
- An **Endowment Fund** was set up within MHAUS to hold funds to be used in the case of a financial need in the future, a contingency plan.
- We held an **online webinar** regarding MH during the year and are planning more in the coming years, initially focusing on ambulatory surgery centers.
- An initiative was begun to develop MHAUS recommendations addressing our customers' concerns about specific areas of concern and MH preparedness guidance, e.g., Preparation of Anesthesia Workstations for MH Susceptible Patients, Temperature Monitoring during Surgical Procedures, and Adverse Effects of Heat and Exercise in Relation to MH Susceptibility, etc.

Breakdown of Expenses October 1, 2011 through September 30, 2012



MHAUS Staff – Who to call?
 Gloria Artist, MH Hotline Coordinator – Sharon Dirksen, PhD, Scientific Officer
 Fay Kovack, Fulfillment Administrator [product orders, MH Let's Save a Life Mini-conferences]
 Lisa Iannello, Development Officer [grant development, donation, program support development]
 Nicole Viera, Inventory/Purchasing/Meetings Administrator [orders, membership] – Michael Wesolowski, PR/Projects Coordinator

Visit our website at www.mhaus.org to **join** and become educated on malignant hyperthermia and **Be Prepared for MH!**

FY 2011-2012 Statement of Expenses	
Personnel & General and Administration	\$ 414,900
Programs, Products, Services	\$ 216,700
Conferences/Meetings	\$ 36,000
North American Registry	\$ 87,020
Professional/Independent Services	\$ 35,000
Association Development	\$ 43,080
Building Expenses	\$ 17,150
Neuroleptic Malignant Syndrome Information Services	\$ 5,750
Fundraising	\$ 1,500
Miscellaneous	\$ 4,900
TOTAL	\$ 862,000

2011-2012 Board of Directors
President: Henry Rosenberg, MD, CPE
Vice President: Mr. Ron Ziegler
Vice President – Scientific Development: Sheila Muldoon, MD
Vice President – Director, NMSIS: Stanley Caroff, MD
Secretary: Steven Napolitano, Esquire
Treasurer: Joseph Tobin, MD
Board Members
Bonnie Denholm, MS, BSN, RN, CNOR
Jennifer Geurts, MS, CGC
Debra Merritt, CRNA, MSN
Ms. Dale Ann Micalizzi
Mr. Michael Paino
Executive Director
Ms. Dianne Daugherty