### **2014 ANNUAL REPORT**

The Malignant Hyperthermia Association of the United States, or MHAUS, a 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, 2012 - September 30, 2013

- Over \$310,000 in salary/benefits, to six individuals
- Over \$137,000 in purchases made from Chenango area businesses and in the surrounding counties in New York State
- Invested over \$11,000 in maintaining a building in Sherburne, NY

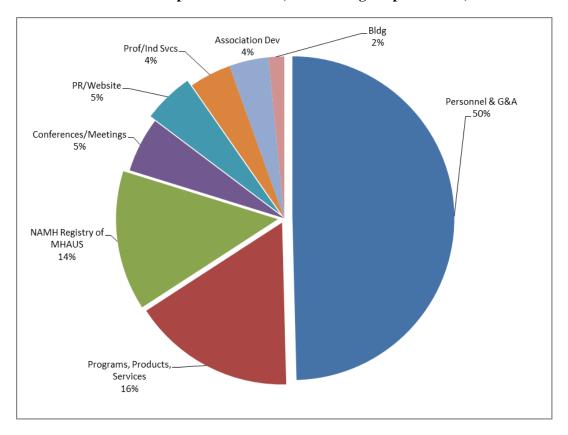
## Products/Programs/Services Offered

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 2012-2013**

- Online course through CMEZone ending with 4,500 unique readers and nearly 3,600 taking the test to assure they understood the content provided.
- An MH Mini-conference held in Florida; Lisa Marie Groetzner spoke on the tragic loss of her young son to MH and the need for MH awareness.
- A Website Oversight Committee (WOC) was put in place to quickly address content concerns on the website using a "dashboard" system which contains a content review system designed for the site.
- Ron Litman, DO, appointed Medical Director of the MH Hotline to focus on improvement of hotline case data capture and promotion of the hotline.
- Stuart E. Lieblich, DMD, joined the Professional Advisory Council to provide an oral and maxillofacial surgeon's perspective to MHAUS materials.
- Georgirene Vladutiu, PhD, joined the MHAUS Board of Directors in January 2013 and brings an expert geneticist perspective to the group.
- Partner Membership Option developed with the Association of Operating Room Nurses (AORN) to make MHAUS membership available to active AORN members at a reduced cost.
- Began offering 50% off active military membership to MHAUS as well as organizational memberships for multiple people at one facility.
- Dianne Daugherty, MHAUS Executive Director, and Dr. Henry Rosenberg, MHAUS President wrote an article for Outpatient Surgery publication on MH preparedness in April 2013.
- Andrew Herlich, DMD, MD, FAAP wrote an article on MH in the ASC and Office-based setting for the August 2013 ASA Newsletter.
- Office-based MH Procedure Manual revised to incorporate new perspectives and insight gained from the joint efforts between MHAUS and the Society of Ambulatory Anesthesia (SAMBA) to design the Emergent Transfer Plan for Office-based Surgicenters and accompanying checklist.
- Determined a Membership Coordinator position should be filled to focus on building our membership base and communicate on a regular basis with the MHAUS membership to better understand their needs in order to meet them.
- Began development of a program entitled MH Prep Check that brings an MH expert to any facility that wants to assure they are prepared for MH and as part of the preparation, the MH expert will present a primer on MH and how to recognize and treat it, watch them complete an MH Mock Drill and offer suggestions when necessary, complete a walk through of the facility, and provide a written evaluation for reference and improvement options. A family dedicated to the mission of MHAUS has given support to begin the distribution of these programs.
- A new resource is being designed to address a patient's concerns when they are diagnosed with malignant hyperthermia. It will focus on answers to questions about what this means to them and their family, testing options, and offer some genetic and insurance resources.

# Breakdown of Expenses October 1, 2012 through September 30, 2013



#### MHAUS Staff as of December 2013 - Who to call?

Dianne Daugherty, Executive Director Gloria Artist, MH Hotline Coordinator Fay Kovack, Fulfillment Coordinator [orders, customer support] Katherine Robertson, Administrative Assistant (part-time) Michael Wesolowski, Development Coordinator

# FY 2012-2013 Statement of Expenses (rounded)

Personnel & General and Administration	\$348,477
Programs, Products, Services	\$114,109
North American MH Registry of MHAUS	\$ 98,083
Conferences/Meetings	\$38,567
Public Relations/Website	\$35,419
Professional & Independent Services	\$29,344
Association Development	\$27,440
Building Expenses	\$11,027
TOTAL	\$ 702,466



# 2012-2013 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
Georgirene Vladutiu, PhD

Visit our website at www.mhaus.org to become an MHAUS Member!

Learn about malignant hyperthermia and Be Prepared for MH!