

# Malignant Hyperthermia Association of the United States (MHAUS)



## Fiscal Year 2008-2009 Annual Report

### MISSION STATEMENT

The mission of The Malignant Hyperthermia Association of the United States (MHAUS) is to promote optimum care and scientific understanding of MH and related disorders.

Prepared by  
Dianne M. Daugherty, Executive Director

*MH Strikes Fast, Be Prepared!*

## **EXECUTIVE SUMMARY**

The Malignant Hyperthermia Association of the US was formed in 1981 as a not-for-profit patient advocacy organization aimed at improving care of patients who are at risk for MH. During this time, MHAUS' programs and efforts have made the medical community more aware of MH and MH-like syndromes. Thousands of patients and their families have been helped directly or indirectly by MHAUS. One hallmark of the progress that has been made in managing MH has been the reduction of mortality from MH from over 70% in the late 1970s to less than 5% at present. Much of this was due to the introduction in 1979 of dantrolene sodium for injection by *Norwich Eaton Pharmaceuticals, Inc.* under the brand name, Dantrium IV®, as well as the education/awareness efforts of MHAUS.

There are many new and exciting developments in the MH world including DNA testing for MH from a blood sample, a better understanding of where and how often MH occurs and, through a variety of new and innovative programs including the MHAUS President's Blog, podcasts, video clips on the website, and policies and procedures for combating MH, among others.

To combat the special problems of dealing with MH in the Ambulatory Surgery setting, MHAUS has partnered with ASC Foundation to develop a consensus on guidelines for the "transfer of care" for an MH patient from an ambulatory surgery center to an emergency room in a nearby hospital. This is a major step toward sharing MH education on a much broader scale.

The work at MHAUS will continue as we search for additional ways to educate both medical professionals and patients about the recognition, treatment and prevention of malignant hyperthermia. We at MHAUS are still concerned that a number of MH deaths occurred in this past year, not all places where triggers are administered have a supply of the antidote on hand, and not everyone is prepared to handle MH. Because of this, we will continue to drive MH education and recognition so that those who might unexpectedly have to deal with MH, will be prepared for it and keep their patient safe.

## **WHAT IS MALIGNANT HYPERTHERMIA (MH)?**

Malignant hyperthermia (MH) is an uncommon and potentially lethal syndrome that is triggered in susceptible individuals by the commonly used potent inhalation gas anesthetics such as isoflurane, enflurane, sevoflurane and succinylcholine, a muscle relaxant. Scientists have not determined the *exact* cause of MH, but continue to investigate evidence that it involves a derangement of the processes that regulate muscle contraction. MH is an inherited disorder and is due to an aberration in the biochemistry of muscle in the MH susceptible when exposed to commonly used anesthetic agents.

An MH crisis appears in susceptible individuals during, or shortly after, application of one of the anesthetic drugs that are known to cause the syndrome. Patients can experience greatly increased body metabolism, muscle rigidity and fever of up to 106°F or more. If not diagnosed quickly and properly treated, an MH crisis may lead to death or organ damage. However, when the antidote, dantrolene sodium for injection, is administered in proper doses used, a negative MH outcome may be avoided. Recent evidence indicates that some MH patients are at risk for MH under other conditions, not related to anesthesia exposure.

### **Laboratory Diagnosis for MH**

The most accurate diagnostic test for MH involves a specialized biopsy from a leg muscle, only available from five centers across North America. MH is inherited with several genetic abnormalities found in some MH patients. The muscle biopsy test remains the "gold standard" to determine MH susceptibility in patients. In 2005 molecular genetic testing for MH was introduced, but only two CLIA-approved laboratories (i.e., government) are available that perform the test. A virtue of this test is that DNA can be extracted from cells found in the blood and searched for the known genetic mutations that predispose to MH. The test is limited at the moment to specific individuals already known to be MH-susceptible and their family members. There are more whose relation to MH is unclear, but progress is being made in clarifying all the genetic changes that can lead to MH.

### **MH Triggers**

Scientists believe the anesthetic agents that will stimulate an MH crisis have been identified. These agents include the volatile gaseous inhalation anesthetics (e.g., halothane, enflurane, isoflurane, sevoflurane, desflurane and methoxyflurane) and the muscle relaxant, succinylcholine. Many drugs have been determined NOT to trigger MH as well. Barbiturates, narcotics (opioids), tranquilizers, local anesthetics, intravenous anesthetic induction agents and the inhaled gas nitrous oxide will not trigger MH, as well as the muscle paralyzing agents pancuronium, atracurium, vecuronium, mivacurium, rocuronium and cisatracurium. Furthermore, it is clear that the vast majority of prescription and non-prescription drugs will not trigger MH.

Despite the knowledge of which agents will and will not trigger MH, the reason why they trigger MH is still a mystery. Not everyone who has MH develops an episode each time a triggering agent is given to him or her. Deaths have occurred even after multiple prior uneventful surgeries. Thus, even patients who have had surgery without complications before, cannot be certain they are not at risk. In some rare cases environmental stressors, e.g., heat and exercise may trigger an MH episode.

### **MH Precautions**

With proper preparedness by both the MH-susceptible and the OR team, when MH occurs during anesthesia, a bad outcome can be avoided in most cases. For medical professionals, this includes being familiar with MH testing protocols, trigger agents, symptoms and proper treatment procedures. MH-susceptible individuals must be aware of triggers and assure they share their complete medical history with their anesthesia care provider. It is highly recommended that MH patients always wear a medical ID tag and assure their hospital/ambulatory center stocks a full 36-vial supply of unexpired dantrolene sodium for injection. Should the “worst case scenario” occur, MH can be successfully managed in virtually all cases with the immediate use of the antidote, dantrolene sodium for injection, and implementing other life-saving measures as outlined and developed by the expert professionals associated with MHAUS.

## **WHAT IS MHAUS?**

The Malignant Hyperthermia Association of the United States, founded in 1981 by four individuals, Suellen Long Gallamore, Owen Davison, Robert Luckritz and George Massik, with the help of Dr. Henry Rosenberg, an anesthesiologist and researcher in malignant hyperthermia, is a not-for-profit patient-advocacy association dedicated to education and training on MH and serves as a resource to families affected.

Today, the almost 2,000 MHAUS members include medical professionals from many disciplines as well as MH-susceptible individuals and their families, many have had first-hand experience with the devastating impact of an MH episode.

As a non-profit organization, our source of revenue includes memberships, additional contributions from patients and their families, medical professionals, hospitals, and ambulatory surgery centers, professional associations and corporations. In fiscal year 2007-2008 total revenue was \$569,890 with 17% supporting administrative and fundraising expenses.

## **GOVERNING BOARD**

A volunteer Board of Directors governs, sets policy, and monitors performance against plans for MHAUS; term of office is for at least one year, but many remain much longer as they have a personal connection with an individual who is susceptible to MH or have a strong interest in the problem.

The Board of Directors has two regularly scheduled board meetings and one two-day strategic planning meeting annually. During FY 07/08, the following meetings were held:

November 12, 2007 10am – 3:30pm	DLA Piper US, LLP	New York, NY
April 25, 2008, 10am – 4pm	DLA Piper US, LLP	New York, NY
September 5-6, 2008	Crowne Plaza Main Line Hotel	Philadelphia, PA

## **PROFESSIONAL ADVISORY COUNCIL**

The Professional Advisory Council (PAC) of MHAUS advises the Board on the formulation of all MH medical policies and responds to inquiries from patients and physicians about malignant hyperthermia. PAC members are anesthesia care providers and other medical professionals, including a number of the world's leading malignant hyperthermia investigators and authorities.

### **MHAUS' GOALS**

- ❖ Educate the entire spectrum of medical professionals so that MH is automatically looked for, guarded against, recognized and properly treated by persons in all of the medical disciplines.
- ❖ Advise and prepare all medical facilities in the United States for prompt diagnosis and immediate treatment of MH episodes.
- ❖ Help MHS patients and their families learn to live with MH susceptibility and offer them the experience and knowledge which has been accumulated about MH.
- ❖ Encourage and support research into MH and MH-like syndromes.
- ❖ To stimulate the development of a noninvasive, accurate, diagnostic test.

### **ONGOING SERVICES**

#### **The MH Hotline—A Patient Lifeline**

The most notable and perhaps most important of MHAUS' services is the MH Hotline. The Hotline provides healthcare professionals with access to anesthesiologists with special expertise in 24 hours per day, 365 days per year. These volunteer hotline consultants provided MH expertise and support to medical professionals in successfully managing an MH crisis over 650 times in this fiscal year. Additionally, the MHAUS staff handled almost 1,000 calls for information, direction and educational materials.

MHAUS, along with a generous grant from the American Society of Anesthesiologists (ASA), funds the MH Hotline and administrates all activities necessary to keep it manned with MH experts and running smoothly. Additionally, MHAUS is responsible for informing medical professionals of the hotline's availability and quick access during an MH emergency.

#### **MHAUS Hotline Consultants**

Michael G. Adragna, MD – SUNY School of Medicine, Buffalo NY  
Gregory C. Allen, MD, FRCPC – Olympia Anesthesia Associates, Olympia WA  
Kumar G. Belani – University of Minnesota Medical Center, Minneapolis MN  
Barbara Bandom, MD – Children's Hospital, University of Pittsburgh, Pittsburgh PA  
James W. Chapin, MD – University of Nebraska Medical Center, Omaha NE  
Brian J. Gronert, MD – Anesthesia Associates of New Mexico, Albuquerque NM  
Andrew Herlich, MD – Temple University Children's Medical Center, Philadelphia, PA  
Richard F. Kaplan, MD – Children's National Medical Center, Washington, DC  
Ronald S. Litman, DO – Children's Hospital of Philadelphia, Philadelphia PA  
Agi Melton, MD – Sierra Anesthesia, Reno NV  
Jordan D. Miller, MD – UCLA Medical Center, Los Angeles CA  
Marshall S. Millman, MD, PhD –Anesthesia/Pain Management Services, Manchester, TN  
Michele Moro, MD – University of New Mexico Health Science Center, Albuquerque, NM  
Jerome Parness, MD – Children's Hospital of Pittsburgh, Pittsburgh, PA  
Harvey K. Rosenbaum, MD – UCLA Medical Center, Los Angeles, CA  
Henry Rosenberg, MD – St. Barnabas Medical Center, Livingston, NJ  
Scott R. Schulman, MD – Duke University Medical Center, Durham NC  
Mohanad Shukry, MD – Children's Hospital of Oklahoma, Oklahoma City, OK  
John Skoog, MD – Mercy Hospital Medical Center, Des Moines, IA  
Lena S. Y. Sun, MD – Columbia University, New York NY

### **MHAUS Hotline Consultants (con't)**

Timothy Tautz, MD – University of California, Davis CA  
Mary C. Theroux, MD – The duPont Hospital for Children, Wilmington, DE  
Joseph R. Tobin, MD – Wake Forest University, Winston-Salem, NC  
Charles B. Watson, MD, FCCM – Bridgeport Hospital, Bridgeport CT  
Denise J. Wedel, MD – Mayo Medical School, Rochester, MN  
Margaret Weglinski, MD – Mayo Medical School, Rochester, MN  
Cynthia A. Wong, MD – Northwestern University Medical School, Chicago IL

### **PROGRAMS AND INITIATIVES**

#### **Educational Programs**

A critical skill to deal with malignant hyperthermia is knowledge of the necessary precautions to take, symptoms to look for, and steps to take, resulting in a positive or negative outcome from an MH crisis. Thus, an essential component of our efforts to conquer MH are specific educational programs to medical professionals covering MH diagnosis and treatment, advice and counseling for MH patients, and informing the healthcare professionals of the latest research in the field. A total of 3,021 packets of educational material were sent out throughout North America during this fiscal year. The following educational programs are provided on an ongoing basis:

- MH crisis protocol posters and pocket cards
- Patient education brochures
- Public relations work to improve MH awareness
- In-service training material in videotape and DVD formats
- Podcasts and Hotline Case of the Month on our website
- Training Procedure Manuals (hospital, ambulatory and office-based versions) proven to reduce the response time in a crisis by up to 50%
- Educational literature for healthcare professionals including OR Nurses, Anesthesia Care Providers, Surgeons, Post-anesthesia Care Nurses, etc.

MHAUS attends and exhibits MH materials at several medical and nursing conferences each year. This year we joined efforts with the *Society for Pediatric Anesthesia* to put on an “MH and Related Disorders” full day symposium, which was attended by well over 150 who remained attentive to the end.

#### **The Communicator—Keeping MH Issues Current**

*The Communicator*, MHAUS' quarterly newsletter, provides current MH information. Articles cover topics ranging from the latest research finding and screening methods to suggestions to help patients deal with various MH concerns. It relates the most current MH information shared with MHAUS via our Professional Advisory Council, Hotline Consultants, Board members, and other contacts. In addition an E Newsletter covering the latest information about MH is published every other month.

#### **MHAUS Website**

The MHAUS website provides direct access to many of our programs and education materials over the worldwide web. An actual face of MH, Greg Glassman, along with his personal story was added to the site. Separate medical professional, patient, about MHAUS, and media pages makes it easier to search. The website remains an integral way to share new programs and offerings, such as the free first year MHAUS membership for anesthesia-related residents, the new MH Crisis Kit, important upcoming MH meetings, a Message Board for patients and medical professionals to share experiences and insights, past issues of *The Communicator* as references, the new President's monthly blog (with almost 2,000 visits), MH testing options, and more. The MHAUS website, has received 626,021 visits this past year (a 186% increase from last fiscal year), with interest increasing via statistics, showing 2,2700,768 page views in this fiscal year.

### **Patient Support Services**

While educational programs address the primary MHAUS mission of reducing MH mortality and morbidity, the needs of MHS patients and their families go well beyond education. MH-susceptible patients require not only practical support in taking the necessary precautions to prevent negative MH outcomes as well as tools to use in sharing with their medical professionals, but also benefit from emotional support as they try to deal with the many fears associated with having MH. MHAUS strives to understand and meet the needs of MHS patients through a variety of ways including:

- MH alert sticker/wristband kit
- MH testing center referral
- MH Mini-conference (this year in Tampa, FL)
- Patient Liaison Committee
- Medical ID tag program - The *Sandi Ida Glickstein Fund* is available for those who need a bracelet, but cannot afford it themselves

### **North American MH Registry of MHAUS**

The North American MH Registry (NAMHR) of MHAUS was established in 1987 and merged with the Malignant Hyperthermia Association of the United States (MHAUS) in 1995. Actual case data are collected by the Registry and entered in sophisticated database in order to better understand the clinical presentation of the syndrome. Dr. Barbara W. Brandom at Children's Hospital in Pittsburgh, PA currently directs the Registry.

The Registry's goal is to acquire, analyze, and disseminate case-specific clinical and laboratory information related to malignant hyperthermia susceptibility. The Registry functions within HIPAA, OHRP, and IRB regulations. Registry data is available for research into MH. Each potential study must have IRB approval from its parent institution, and approval from our Scientific Advisory Committee. Scientists and researchers not associated with MHAUS may have access to the data with appropriate approval

#### **Objectives of the Registry are to:**

- Maintain a central database of individuals with MH susceptibility and similar syndromes.
- Provide information storage and analysis services to MH diagnostic referral centers for standardization and validation of MH diagnostic testing procedures, including genetic tests.
- Investigate the epidemiology of MH in order to improve diagnosis, treatment, and prevention of MH episodes.
- Give a registered person the security of knowing that there is a central repository of information concerning their MH susceptibility status.

### **Molecular Genetic Testing Progress**

The simple, affordable diagnostic test remains of interest to patients and medical professionals alike. MH testing can be done at two CLIA-certified laboratories, in Marshfield, Wisconsin and Pittsburgh, Pennsylvania. The test is not applicable for all patients since not all the mutations associated with MH are known. A brochure is available describing both types of testing. Molecular genetics, although in its infancy, offers accurate diagnosis of susceptibility to MH using a blood test and provides insight into the mechanisms of the disorder. MHAUS continues to support a program to provide support to patients who can't afford to have genetic testing done and fit the financial need criteria.

### **Promotion of MH Scientific Research**

MHAUS supports scientific research into MH through direct research grants and financial support of the Registry and as a solicitor of third-party funds for important MH research initiatives.

### **Neuroleptic Malignant Syndrome Information Service (NMSIS)**

NMSIS is a unit of MHAUS founded in 1997 by MHAUS along with a group of prominent psychiatrists with extensive experience in treating NMS. Neuroleptic Malignant Syndrome (NMS) is an uncommon but potentially life-threatening disorder associated with the use of antipsychotics or other centrally-active dopamine antagonists, that is characterized by disturbances in mental status, temperature regulation and autonomic and extrapyramidal functions. The NMSIS component of MHAUS is governed by a volunteer Professional Advisory Council and includes several of the world's leading NMS investigators and authorities.

In 1997 an NMS Hotline was established with volunteer NMS experts from psychiatry and anesthesiology to help medical professionals during an NMS emergency.

In this fiscal year, NMSIS 1) again made available a *Promising New Investigators Travel Award*, to encourage research on psychotropic drug safety and side effects; 2) began work on a consensus among the experts in NMS and Emergency Care medicine as to the appropriate guidelines to follow in an NMS case, 3) offered Speakers Bureau of NMS experts for hospitals and associations searching for NMS information and updates, 4) enjoyed a surge of interest in the NMSIS website with almost 118,000 visitors, 5) provided educational literature to patients, caretakers and professionals, and 6) continued to help others dealing with an NMS event through the NMS Hotline – 52% of calls were thought to be probably/definitely NMS.

### **NMS Hotline Consultants**

Stanley N. Caroff, MD – VA Medical Center, Philadelphia, PA  
Brendan T. Carroll, MD – VA Medical Center, Chillicothe, OH  
Joseph A. Cheong, MD – University of Florida, Gainesville, FL  
Mohit Pawan Chopra, MD – University of Arkansas for Medical Sciences, Little Rock, AR  
Andrew J. Francis, MD – SUNY at Stony Brook Health Sciences Center, Stony Brook, NY  
Michael Gliatto, MD – VA Medical Center, Philadelphia, PA  
Sanjay Gupta, MD – Olean General Hospital, Olean, NY  
Ronald J. Gurrera, MD – VA Boston Healthcare System, Brockton, MA  
William B. Lawson, MD – Howard University Hospital, Washington, DC  
James L. Levenson, MD – Virginia Commonwealth University School of Medicine, Richmond, VA  
Ahsan Mahmood, MD – TLC Health Care Network, Irving, NY  
Stephan C. Mann, MD – Central Montgomery MH/MR Center, Norristown, PA  
Patricia I. Rosebush, MD – McMaster University, St. Joseph's Hospital, Hamilton, Ontario, Canada  
Henry Rosenberg, MD – St. Barnabas Medical Center, Livingston, NJ  
Charles Watson, MD – Bridgeport Hospital, Bridgeport, CT  
Ikwunga Wonodi, MD – University of Maryland School of Medicine, Baltimore, MD

### **NEW INITIATIVES**

#### **“Faces of MH”**

This initiative began with a “stock photo” of a man and his son to drive home the point to the customers of MHAUS that MH can happen to you or someone you know, thus putting a “face” on MH. Taking this a step further, we began searching for “actual” MH survivors to post on the website along with their personal story to personalize the message and drive our theme of “MH is a Crisis Best Treated by Prevention and Preparation” and by keeping it in mind will help to keep patients safe and save lives. During this fiscal year we were able to gain Greg Glassman’s before and after picture with his mother relating the personal MH story; encouraging others to come forth and share their stories as well.

#### **Speakers Bureau**

MHAUS speakers bureau continues to grow with 8 speakers relating MH recognition and treatment needs at medical association meetings, hospital in-service presentations, and to other groups keenly interested in MH education across the United States. The expert speakers share information on MH crisis management, MH testing options, a mock drill of an MH episode, and questions and answers from the audience. Medical professional who have ever dealt with a case of MH understand the need for this presentation, as watching a patient’s physiology deteriorate over minutes due to MH is one of the most frightening and potentially devastating events he or she may experience in her/his career. MHAUS offers limited grant funding for this program as we feel it is an important step in our mission to share MH education and to keep patients safe.

### **MHAUS Consensus Report on Managing MH Outside a Hospital Environment**

The findings from the MH Consensus Meeting were developed into a final report, which was agreed to by all in attendance. This report will be developed into a final booklet entitled "Malignant Hyperthermia: A Clinical Practice Protocol" to be printed and made available in the next fiscal year.

### **MH Muscle Biopsy Video**

The Executive Director traveled to our MH Biopsy Testing Center in Winston-Salem, NC to watch an actual MH biopsy and to videotape it to be placed on the MHAUS website as a tool for medical professionals and patients in their understanding of exactly how the biopsy is performed, what the patient should expect the final scar might look like, how large is the piece of muscle excised, how the actual laboratory test is performed to determine whether or not the patient is MH susceptible. This final product will be placed on the MHAUS website in the next fiscal year as a video clip for all to view. This is another example of listening to our customers to understand their needs and try to deliver an answer for them.

### **MH Mini-conference**

During this fiscal year there were deaths from MH, one in particular, Stephanie Kuleba, happened in Florida and received widespread media attention as her parents wanted to bring this MH tragedy to the public to try to help others to not go through the same horror. MHAUS shared as much information with the family as possible and when interest was expressed by medical personnel in Tampa, Florida to hold the MH Mini-conference in their state to further bring attention to this uncommon disorder, we were only too happy to oblige. The meeting was well attended and a mock drill was held to clarify just how fast an MH event occurs and highlighted the need to be ready and prepared to respond quickly.

### **MH Crisis Kit**

A kit was developed containing the "most requested" items in order to offer the tools found to be most helpful in an MH event: an MH procedure manual, the Emergency Therapy Laminated Poster, an In-service Kit, a medical packet of recent brochures on MH, and membership to MHAUS to remain "in the know" on all the latest news in the MH world, which has been very well received by our medical professional customers.

### **Canadian Anesthesiologists and MH-susceptibles**

As there has not been an active MH educational presence in Canada for a number of years, a dedicated effort was made to reach out to the many anesthesiologists and MH-susceptibles and their families in this country. We sent letters in a major mailing to all the Canadian hospitals to make them aware of our presence and willingness to share MH educational materials and help through our MH hotline. Plans for the coming fiscal year will further drive this particular area.

### **Facebook Page for MHAUS**

MHAUS has placed a major focus on the internet world and is delving into new ways to reach our present audience and expand our reach to those who may not know us or understand our mission. Toward this end, the PR/Projects Manager has focused his efforts on broadening the scope through this medium and developed not only a Facebook page for MHAUS to enter us into this quickly growing area, but has also set up a Cause Page to allow those visiting the Facebook Page to donate to the cause and to post questions to other MH susceptibles and MH experts. He continues to keep the site "live" with pictures from meetings and happenings in the MHAUS world, shares news updates on the stories and medical articles related to MH and similar disorders, and relays interesting MH facts and statistics as they develop. We expect this area to continue its strong presence.

## **MHAUS LEADERSHIP**

### **Board of Directors in 2007-2008**

Henry Rosenberg, MD, CPE, President  
Sheila M. Muldoon, MD, Vice President for Scientific Development  
Ronald J. Ziegler, Vice President  
Steven V. Napolitano, Secretary  
John L. Blair, Treasurer  
Stanley N. Caroff, MD, Vice President – Director, NMSIS  
Christina M. Duetsch, MS, RN, CS-P  
Debra R. Merritt, CRNA, MSN  
Joseph R. Tobin, MD  
C. Douglas Webb, PhD

### **Professional Advisory Council in 2007-2008**

Paul Allen, MD, PhD – Brigham & Women's Hospital  
Barbara W. Brandom, MD—University of Pittsburgh  
Patricia Deuster, PhD, MPH – Uniformed Services University of the Health Sciences  
Robert T. Dirksen, PhD—University of Rochester  
Gerald A. Gronert, MD—Professor Emeritus, UC-Davis  
Susan Hamilton, PhD – Baylor College of Medicine  
Paul A. Iaizzo, PhD—University of Minnesota  
Jeffrey A. Kant, MD, PhD—University of Pittsburgh Medical Center  
Richard F. Kaplan, MD—Children's National Medical Center  
Marilyn Green Larach, MD—Pennsylvania State University  
E. Jane McCarthy, CRNA, PhD—FDA, Center for Drug Evaluation & Research  
Sheila M. Muldoon, MD—Uniformed Services University of the Health Sciences  
Henry Rosenberg, MD—Saint Barnabas Medical Center  
Daniel I. Sessler, MD—University of Louisville  
Professor Albert Urwyler, MD—University of Basel, Switzerland  
John A. Yagiela, DDS, PhD—University of California, Los Angeles

### **MHAUS Administrative Office**

Dianne M. Daugherty, Executive Director  
Gloria B. Artist, Hotline Coordinator  
Sharon Hirshey Dirksen, PhD, Scientific Officer  
Fay F. Kellogg, Fulfillment Administrator  
Diane Van Slyke, NMSIS Project Coordinator  
Nicole E. Viera, Database Administrator  
Michael Wesolowski, PR/Projects Coordinator

### **North American MH Registry of MHAUS**

Barbara W. Brandom, MD, Registry Director  
Michael Young, Technical Manager  
Kristee Adams, Administrative Assistant

### **Patient Liaison Committee**

Lydia Friedman, Chairperson  
Janet Lacey, RN  
Mary McNulty  
Mary Masimore, RN, BSN, MS, CNOR

## **SUMMARY**

For close to three decades MHAUS has provided relevant, timely and expert information concerning MH and MH like syndromes to patients and the medical community. Much of the information is offered free of charge or at modest cost. Increasingly sophisticated and focused means of delivery of educational and practical information is provided each year. The organization is indebted to the members, the many contributors and the expert clinicians and scientists who contribute their time to insuring that patients do not suffer ill consequences from these syndromes.

