MHAUS Loses Dick Hillman, Past Executive Director & Driving Force Behind MHAUS

by Dallas Pennington
former MHAUS President

We were all saddened to hear about the death of Dick Hillman, who was such an integral part of the growth and success of MHAUS. Our sympathies and best wishes are with his wife, Barbara, his children and grandchildren.

Dick came to MHAUS as the new Executive Director after retiring from Procter & Gamble Pharmaceuticals, formerly Norwich Eaton Pharmaceuticals, where he had been the Dantrium Product Manager and Director of Marketing. Dick had an MBA in Marketing and had had a long and very successful experience in the Pharmaceutical and veterinary pharmaceutical industry.

Dick really brought MHAUS into the modern era of association management. Dick first secured a substantial grant from Procter & Gamble, which enabled him to move the organization’s offices from a home setting in Connecticut to a modern office facility in Sherburne, New York.

In the new location, he instituted a new system of management, which included forecasting, budgeting, fundraising, scientific development, and patient and physician education. Dick encouraged Board expansion and brought on new employees – including Janice Bays and Shari Williams, who later brought in Dianne Daugherty – all of whom have subsequently been excellent Executive Directors.

Dick’s drive helped get MHAUS on the track to becoming the very successful and effective life-saving organization that it is today.

Dick was a wonderful, intelligent and generous man with a great sense of humor and a special way about him that drew you to him. He always gave you a sense of confidence. He was an accomplished wood working craftsman, was an inveterate reader, he loved to sing, and was a stalwart member in his church. Dick loved people and dogs and most especially, his family.

Dick Hillman will be remembered by all who knew him and will be sorely missed.

MHAUS has established a Memorial Fund in the name of Dick Hillman. Those wishing to contribute may call the MHAUS office at (607) 674-7901. 

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The Malignant Hyperthermia Association of the United States (MHAUS) is a not-for-profit organization dedicated to reducing the morbidity and mortality of malignant hyperthermia and other heat-related disorders by: improving medical care related to MH; providing support information for patients; and improving the scientific understanding and research related to MH and other kinds of heat-related syndromes.

For more information or for materials on malignant hyperthermia or MHAUS’ programs, call 607-674-7901; write MHAUS, PO Box 1069, Sherburne, NY 13460; or visit us on the Internet at www.mhaus.org.
MHAUS To Bring MH Consultant Workshop To This Year’s ASA Meeting, Oct. 17-21

At this year’s American Society of Anesthesiologists meeting, MHAUS will have a workshop on what it means to be an MH Hotline Consultant, drawing on cases from the MH Hotline. Volunteers will play the role of the Hotline Consultant with an actual Hotline Consultant portraying the caller.

“We anticipate the workshop to be open to up to 60 people,” said Dr. Henry Rosenberg, MHAUS President. “Not all will be in the hot seat though. Some will be observers and participate in the discussions. There will be two rooms and the session will last for three hours on one day.”

While anesthesia care providers may review the basic knowledge related to MH several times in a career, this workshop will take the participants’ knowledge to the next level by seeing the potential MH patient through the eyes (or ears) of an MH Hotline Consultant.

The caller to the MH Hotline may have excellent resources and knowledge, or may not remember much about MH, and the resources at their disposal may not seem up to the task of managing the patient. Similarly, a number of common syndromes mimic MH such that the Hotline Consultant may have to either provide reassurance or help the caller manage a non-MH life-threatening crisis.

Under the direction and mentorship of experienced Hotline Consultants, participants will serve as telephone consultants to simulated practitioners calling with various dilemmas that have actually presented over the years. Each simulated conversation will be followed by a small group discussion.

“We plan to cover diverse topics including MH mimics, mas-seter spasm, suspected MH in the office/free standing surgicenter, coaching on resource management, and the anxious caller,” said Dr. Rosenberg.

MHAUS will soon be rolling out a comprehensive exportable curriculum for MH, and this course would be suitable for potential instructors in simulation centers and other teaching centers, who will be expected to have a high level of mastery of the subject matter.

“Additionally, at a time when various ASA committees are considering other hotlines to help callers threatened by lawsuits, impairment and other issues, the lessons learned from the MH Hotline have taken on new importance,” said Dr. Rosenberg.

Hotline Consultant volunteers in the workshop include Dr. Rosenberg, from St. Barnabas Medical Center in Livingston, NJ, Dr. Mary Theroux, from The duPont Hospital for Children in Wilmington, DE, Dr. Kumar Belani from Fairview University Medical Center in Minneapolis, MN, Dr. Charles Watson from Bridgeport Hospital in Bridgeport, CT, Dr. Mohanad Shukry of Children’s Hospital of Oklahoma in Oklahoma City, OK.

“Although this has never been done, it will be a lot of fun and interesting as well,” Dr. Rosenberg said.

Goal
Participants will advance their knowledge of the real world presentations of MH and MH-like syndromes in the context of telephone consulting, with its inherent limitations, including lack of visual and environ-mental cues and lack of non-verbal communication hints.

Objectives
Participants will be able to:
1. Analyze the key elements of an MH-related problem
2. Communicate diagnostic and treatment plans in the treatment of MH
3. Provide guidance in post episode management of MH-susceptible patients
4. Discuss the record-keeping associated with a Hotline call and its relationship to the MH Registry
5. Differentiate MH from other metabolic emergencies in the Perioperative period
6. How the MH grading scale is used in analysis of MH cases
7. Understand how the MH hotline works

Do you have an MH survival story? Tell us about it and include a before and after picture. Visit the MHAUS website at www.mhaus.org and click on “Faces of MH” in the lower left of the patient or professional section, located just above the “Facebook” link.
Guidelines For Management Of The Fetus At Risk For MH

MHAUS has issued guidelines for management of the pregnant patient not believed to be at risk for MH, but whose partner is susceptible to malignant hyperthermia.

The question of the best anesthetic management for labor and delivery of a parturient who is not MH susceptible herself but whose partner is believed to be MH susceptible is largely theoretic since there are no human or animal clinical studies related to this situation. There are also no cases reported of a fetus of such parents developing a peripartum MH crisis. Nevertheless, since this situation does occur with some frequency, the following are suggested guidelines for anesthetic management. MHAUS was pleased to learn that the Society for Obstetric Anesthesia and Perinatology (SOAP) has provided a link from their website to these guidelines on the MHAUS website.

PRIOR TO DELIVERY:
If at all possible, the father’s MH susceptibility should be confirmed by review of medical records. If a genetic test has been done and a known causative mutation found, that mutation can be sought in the fetus prior to delivery (chorionic villus sampling or amniocentesis). However, this course is not recommended by most MH experts at the present time unless the procedures are being undertaken for other reasons. Consultation with the local anesthesiologist and an MH expert, e.g. biopsy center director, MH hotline consultant or member of the MHAUS Professional Advisory Council is recommended prior to delivery.

ANESTHETIC MANAGEMENT OF A NON-MH SUSCEPTIBLE WOMAN CARRYING A POTENTIAL MH-SUSCEPTIBLE FETUS FOR SURGERY DURING PREGNANCY:
If the pregnant woman requires non-emergent surgery at any point in the pregnancy, a non-triggering anesthetic should be employed, such as local, nerve block or epidural or spinal anesthesia as long as it is accomplished in a timely manner. If a general anesthetic is indicated, a total intravenous anesthetic is recommended with all ASA-mandated monitoring in place, including core temperature monitoring. Fetal monitoring should follow standard guidelines. Dantrolene should not be administered in preparation for surgery, labor and delivery.

LABOR AND DELIVERY:
The labor and delivery should be conducted at a site where anesthesia staff is present and immediately available. The anesthesia providers should be notified of the arrival of the patient on the Labor and Delivery Unit as soon as she is admitted.

Continuous epidural analgesia is highly recommended for labor and delivery. If a Cesarean delivery is indicated in a patient who does not have an epidural catheter in place, neuraxial (spinal, epidural, or combined spinal-epidural) anesthesia is recommended if not otherwise contraindicated. If a general anesthetic is indicated, a non-triggering anesthetic technique should be employed, although nitrous oxide may be used with an anesthesia machine that has been prepared for an MH susceptible patient.

If a rapid sequence induction is needed, succinylcholine, although a known MH trigger, may be administered* since so little of the drug crosses the placental barrier. However, an appropriate intubating dose of rocuronium, i.e., 1-2 mg/kg, may be used in place of succinylcholine. An awake intubation is also an option. After delivery, volatile anesthetic agents may be administered to the mother.

If uterine relaxation is necessary prior to delivery, nitroglycerine (NTG), 250 µg IV may be used, or NTG sublingual spray, one puff. The dose may be repeated. Another alternative is terbutaline 2.5 mg SQ.

POST DELIVERY
Following delivery, an umbilical blood sample may be obtained for genetic analysis for MH susceptibility in those cases where the father has been shown to harbor a known MH causative mutation. In this case the DNA diagnostic center should be contacted prior to obtaining the blood sample.

If the father is not known to harbor a known mutation the determination of whether to obtain a blood sample for genetic analysis is complex and requires consultation with a MH hotline consultant or member of the MHAUS Professional Advisory Council.

In the absence of any medical problems, the mother and baby should be treated no differently than normal.

* A few MH experts do not recommend use of succinylcholine in this circumstance.

REFERENCES:
MHAUS Faces The Future With Renewed Enthusiasm

by Dianne Daugherty
MHAUS Executive Director

Although the present economic climate brings concern over how we are going to face the future and continue our recent strong growth and development, we are confident that those who have supported our efforts will continue to see the ongoing critical need for support of MH education. Our members, those involved in the medical field as well as families who have suffered in the past from MH, continue to come forward in support of MHAUS. We all work together as an organization which truly saves lives! We have found that education is empowering when put in the hands of people who care.

MHAUS is focused on the future and will continue to make a difference by driving our energies toward our customer’s needs. Identified needs will be met through the focused efforts of MHAUS staff and active participation and insight from the board of directors, the NAMH Registry personnel, the Professional Advisory Council, and the Hotline consultants. Through these internal forces, we will make a difference! We will cultivate a stronger base by looking inward at what we do best, and do more of it; consider the large cadre of MH experts available to us and expand the methods used to share their knowledge; and gain support from our members and donors who believe in what we can accomplish together.

We have already come a long way: DNA testing for MH from a blood sample, in a patient with specific qualifying criteria, now offers a less invasive option for those specific few families. Although it is not an overall answer for everyone, it is a start! Through a variety of new and innovative programs - the MHAUS President’s Blog, podcasts, video clips on the website – we have helped to advise the general public and medical community on the latest happenings in the MH field which could impact their lives.

To help those facilities eager for more information on MH preparedness, we have joined efforts with other groups also driven by patient safety. Recently, we placed major focus on Ambulatory Surgery Centers and their need for a consensus on Guidelines for the "transfer of care" of an MH patient from an ambulatory surgery center to an emergency room in a nearby hospital. We will, hopefully, have something concrete to offer as a result in the coming months.

The “Faces of MH” initiative began with a “stock photo” of a man...
and his son to drive home the point that MH can happen to you or someone you know. We put a “face” on MH by taking this a step further and gaining the initial agreement of one of our MH-susceptible family members, Greg Glassman, to use his before and after picture. His mother related her personal recollection of his MH story and thus encouraged others to come forth and share their stories as well. If you have a friend who might benefit from our site or is MH-susceptible and has a story to tell, have them call us.

The MHAUS speakers bureau offers experts to talk about MH recognition and treatment needs at medical association meetings, hospital in-service presentations, and to others keenly interested in MH education. They share information on MH crisis management, MH testing options, MH mock drills, and handle questions and answers from the audience. Any medical professional who has ever dealt with a case of MH understands the need for this kind of presentation, as watching a patient’s physiology deteriorate over minutes due to MH is one of the most frightening and potentially devastating experiences in her/his career.

The findings from a recently held MH consensus meeting were developed into a final report which took shape as a short booklet entitled "Malignant Hyperthermia: A Clinical Practice Protocol". This booklet is now available as another reference on MH from the experts, to all new MHAUS members and those requesting it. It is concise, enlightening and covers a broad scope of helpful insight and recommendations on a preparation plan for MH.

An MH Biopsy Test was videotaped at one of the MH Testing Centers (Winston-Salem, NC) as a tool for medical professionals and patients considering testing options. The final product is now available on the MHAUS website as a video clip. (See article, page 7).

Unfortunately, in the past 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 in their efforts to assure others would not have to endure the same experience and heartbreak. MHAUS shared as much information with the family as possible and continues its efforts in this area by offering MH Mini-conferences – this year two locations are planned in Schenectady, NY, and Oklahoma City, OK, for September 2009. This is an opportunity for medical professionals and patients to come together to learn about MH, communicate their experiences, share feedback and develop a broader network of those who care.

The Internet world is becoming an integral part of our business by allowing quick access to information for our customers and the immediate distribution of breaking news. The MHAUS website, found at www.mhaus.org shares pictures from recent MHAUS meetings and events as well as medical articles related to MH and similar disorders. We expect even stronger growth via this venue, and welcome any feedback/suggestions from those visiting the site.

So there you have it! We at MHAUS will continue to forge ahead and make great things happen; with your help, monetary support and feedback on improvements, you can be an integral part of the MHAUS growth process! If you are a member, keep in touch ... if you are not a member, join us!

“How Do I Counsel My Patients” Slide Show Now Available

A new slide show is now available on the MHAUS website to help guide medical professionals in discussing with their patients whether they should be referred for additional diagnostic testing relating to MH-susceptibility (MHS).

The slide show was completed under the direction of MHAUS Scientific Officer Dr. Sharon Dirksen, with input from MHAUS Hotline Consultants, Professional Advisory Committee members, and genetic counselors. The streamlined, easy-to-read guideline provides a quick reference for most any question related to MH-susceptibility testing.

A link to the slide show is available on both the medical professional and patient section of the MHAUS website. To view the slide show now, visit http://medical.mhaus.org/PubData/PDFs/dx_testing_options.pdf

Correction

In the Winter 2009 issue of The Communicator the Wood Library Museum of the ASA should have been credited for providing the picture of Dr. Beverley Ann Britt on page 6 for the article entitled “Dr. Britt Helped Bring MH Awareness To Canada.”
Video Shows What Happens During MH Muscle Biopsy?

by Dianne Daugherty
MHAUS Executive Director

As Executive Director of MHAUS, I had never seen an actual muscle biopsy test for MH susceptibility. To be sure, many of our MH experts were very helpful in explaining the process to me in detail, but as a kinesthetic learner, I felt I was not grasping the entire process. I wanted to be able to share specifics only gained by “being there” with staff and people calling the MHAUS administrative office for answers to biopsy test questions. I felt that insight from a layperson’s viewpoint could be helpful and reassuring.

As fortune would have it, I happened to speak to a very nice lady via telephone. She was looking for information on an MH testing center, as she had been advised her family was considered MH susceptible, and wanted to confirm whether she was personally at risk for MH – for her family’s sake. In our conversation, she decided she would contact Dr. Tobin at the Wake Forest Medical Center’s biopsy center in North Carolina to arrange her test.

Shortly thereafter, Dr. Tobin made the necessary arrangements to allow me to actually watch an MH biopsy and offered a number of dates for scheduled tests. As fate again came into play, the test that fit my schedule turned out to be the lady I previously spoke with on the telephone!

During the early morning of the test, I was able to meet the patient, listen to the process being conveyed, talk to the “very tolerant” physicians and nurses involved with the procedure, and take digital pictures while the critical video was being recorded. I then followed the muscle specimen to the lab where the process was explained to me by Marina Lin, Research Associate, as she immediately prepared and put the muscle through the specific tests designed to determine MH susceptibility. Our patient happened to test positive.

After months of focused efforts by Dr. Tobin, Ian Saunders, and Will Safrit at Wake Forest, and myself to reduce the entire video to an appropriate length suitable for viewing by the visitors to the MHAUS website at www.mhaus.org, we were able to produce a final video clip several minutes in length showing an actual muscle biopsy procedure – from preparing the patient for the invasive operation to the harvesting of the specific bundle of muscle – and then on to the laboratory to watch the muscle being put through preparation, development of basal tension, and perfusion with buffer containing halothane and then caffeine, and the resulting charting on the screen throughout the test. Trying to capture excessive tension of the muscle’s “twitch,” which is the “visual” sign of MH, was an integral part of the whole process. In the final product, we were able to incorporate charts that clearly showed the graphic representation of the strength of the muscle contracture.

We placed explanatory subtitles at the bottom of each portion of the video clip to clarify what is happening during that section of the video. We gained feedback from our Professional Advisory Council and MH Hotline Consultants to apply their suggestions, where we could, to improve the final product. Within the next six months, we hope to add audio to the presentation as well. In this way, we will be serving the needs of as many of our clients as possible.

Additionally, we have received help from a friend at Methapharm, Inc. in Canada to translate the subtitles into French. Dr. Tobin will also be overseeing translations into Spanish, Portuguese, German and Russian, Chinese and Japanese in the near future.

We feel this new addition to the website will be helpful to medical professionals in discussing options with their patients who are considering MH testing, and to patients and their families as clarification on what exactly is involved when you decide to have a muscle biopsy procedure.

The presentation is graphic and explicit, thus it is important that those viewing it online consider whether it is appropriate for impressionable eyes. Being an informed patient armed with as much knowledge as possible when discussing your case with your medical provider is an important step to remaining safe through surgery. After all, that is what MHAUS is all about – PATIENT SAFETY!
MH & Related Abstracts At The 2008 ASA Meeting

by Sharon Dirksen
MHAUS Scientific Officer

American Society of Anesthesiologists’ (ASA) 2008 Annual Meeting abstracts, presented in Orlando, Florida this past fall, carried strong appeal for those interested in furthering their understanding about MH or learning about advances surrounding the care and treatment of MH-susceptible (MHS) individuals. The following summary provides some highlights.

CURRENT PRACTICE

MH Presentation and the Importance of Early Diagnosis

The North American Malignant Hyperthermia Registry (NAMHR) of MHAUS continues to provide a rich information resource for studies which aim to improve our understanding of MH. Two studies which utilized this valuable database for such a purpose were presented by Dr. Marilyn Larach (Penn State College of Medicine, Hershey, PA) and colleagues.

- In one study, the widely held belief – that an increase in core body temperature is a late sign of MH – is called into question. After reviewing almost 300 MH cases, these researchers found that in almost two-thirds of these MH episodes, a rapid temperature increase or elevated temperature was, in fact, an early sign of MH!

- A second study helps us to understand why it is that some MH episodes are accompanied by serious complications, like organ dysfunction, while others are not. The researchers carefully analyzed almost 200 MH episodes, one-third of which involved serious complications. They looked for differences between patients who experienced serious complications and those who did not, with respect to patient and treatment characteristics and type of anesthetic utilized. The authors concluded the following factors were associated with an increased chance for serious complications:
  - Temperature increase
  - Delay in treatment
  - Increase in MH event severity

These studies indicate that core temperature can rise early and rapidly during an MH crisis, which can lead to serious complications. Taken together, these data highlight the importance of reliable core temperature monitoring and early detection of temperature elevation. In addition, as our ability to quickly diagnose and treat MH improves, so should our ability to prevent life-threatening complications from MH and thus improve survival.

Importance of Preparation and Education

We at MHAUS have often noted that MH is a disorder best treated by education and preparation. Lessons learned from Dr. Larach’s abstracts serve to underscore this message.

In addition, data presented by Dr. Krivosic-Horber and colleagues (Hospital Jeanne de Flandre, Lille, France) also illustrated the positive impact of education and preparation. Their study followed the changes in mortality rate due to MH over a time period spanning almost 40 years. Notably, after implementation of a mandatory requirement in 1989 that adequate supplies of dantrolene and guidelines for MH management be readily available, a dramatic decrease in mortality was observed. Beyond any doubt, preparation and education can be credited with saving lives.

RESEARCH

Genotype-Phenotype Correlations

The genetic makeup (genotype) of an individual plays an important role in determining his/her physical and biological characteristics (phenotype). It is well-known that changes, or mutations, in an individual’s DNA code for the skeletal muscle ryanodine receptor (RYR1) gene are associated with the development of susceptibility to MH, a condition not apparent until triggered by certain anesthetics. It is also well-known that mutations in this same gene are associated with other muscle disorders, such as central core disease (CCD) and multi-minicore disease (MmD), conditions with noticeable symptoms such as muscle weakness and looseness of joints. Interestingly, there are even some RYR1 mutations that have been found to be responsible for both MH susceptibility and CCD. As research in this area progresses, so does our growing appreciation for the broad spectrum of conditions, or phenotypes, for which various mutations in RYR1 may be responsible.

Research presented by Dr. Henrik Rueffert and colleagues (University Hospital, Leipzig, Germany) explores this genotype-phenotype relationship. Dr. Rueffert’s team examined a large family whose members experienced mild muscular symptoms in an attempt to figure out whether their symptoms were related to MH-susceptibility or other structural changes in their muscles. These

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researchers found that about one-third of the family members harbored the same RYR1 mutation, a mutation known to confer susceptibility to MH. In addition, these individuals also displayed minor structural changes within their muscle fibers. The authors concluded that this known causative mutation may not only be responsible for conferring susceptibility to MH, but may also be associated with the muscle symptoms and structural changes observed in this family.

Even more intriguing are the questions brought to bear by Dr. Sheila Muldoon's research at the Uniformed Services University of the Health Sciences (USUHS, Bethesda, MD) in which she and her colleagues evaluated two fatal 'MH-like' episodes which occurred in children during a febrile (associated with high temperature) illness. Not only did these 'MH-like' episodes occur without exposure to anesthetic triggers, but it was later discovered that these two unrelated children shared the same RYR1 mutation! Could it be that this genetic mutation confers susceptibility to 'MH-like' events brought upon by non-anesthetic triggers, such as fever? Can other stresses (eg., heat, exercise) or RYR1 mutations lead to anesthetic-free MH episodes?

The determination of the significance of a gene mutation can be quite complex. Scientists must evaluate whether the mutation is present in individuals who are not affected with the condition in question. They must also conduct studies to determine whether the mutation causes an important change in the protein's function (in this case, the RYR1 protein). The importance of functional characterization of RYR1 mutations was also reinforced through the presentations provided by both Dr. Bayarsaikhan (USUHS, Bethesda, MD) and Dr. Ichihara (Tokyo-Rinkai Hospital, Tokyo, Japan) and their colleagues. Furthermore, the results of Dr. Bayarsaikhan’s research suggest that ethnicity may play a role in determining the frequency or expression of changes in the RYR1 gene. Thus, the impact of one’s genetic background, including ethnic grouping, must also be considered.

To be sure, more research is required to establish a full inventory of characterized RYR1 gene mutations and to interpret how a particular genotype translates into a resulting phenotype. As a full international compendium of RYR1 mutations continues to grow, so should our understanding of their significance.

**Statin Drugs: Are they Safe in MHS Individuals?**

As in all areas of science, findings from one research study may directly impact future research projects, in related or unrelated therapeutic areas. A study presented by Dr. Capacchione and his colleagues at the USUHS (Bethesda, MD) illustrates this point. His team was intrigued by previously published work describing muscle breakdown/toxicity caused by cholesterol-lowering drugs (commonly referred to as statin agents).

Since muscle breakdown is associated with MH, they hypothesized that the muscle of MHS individuals may be more sensitive to statin toxicity. The results of their study indicated that MHS muscle was indeed more sensitive to the statin agent tested than normal muscle. These results suggest the use of caution when prescribing statin agents to individuals with any muscle disorder, apparent or otherwise.

... AND DEVELOPMENT

Currently, diagnostic testing options for the evaluation of an individual's susceptibility to MH include muscle contracture and genetic testing (identification of mutations in the RYR1 gene). Although considered the ‘gold standard,’ many patients refuse to undergo the muscle contracture test because it requires a muscle biopsy, a procedure which is invasive, painful, and costly. Since genetic testing (which requires only the collection of a blood sample) is not recommended for many individuals as a first step in determining susceptibility to MH, alternatives to the muscle contracture test are strongly desired.

In view of this desire, Dr. Bina and his colleagues at USUHS (Bethesda, MD) are working to develop a new minimally-invasive test, one that requires only the collection of a blood sample from the subject in question. Since the RYR1 is expressed in a certain type of blood cell, Dr. Bina’s research team is evaluating whether these cells can be used to assess RYR1 function. Initial studies indicate that this model can be used as an indicator of an individual’s susceptibility to MH. More work is needed to determine the accuracy of this test; however, its potential as an alternative, non-invasive and cost-efficient diagnostic test for MHS is indeed encouraging.

It will be interesting to follow the progress of these research projects in full, peer-reviewed publications that are sure to result from these poster presentations. The more we learn about MH and related fields, the better able we will be to make swift progress in understanding the disorder and in providing improved diagnosis and care of MHS individuals.
The North American Malignant Hyperthermia Registry (NAMHR) of MHAUS has completed a move to its new location at Mercy Hospital, in the University of Pittsburgh Medical Center, in Pittsburgh, PA. The 1-888-274-7899 number and www.mhreg.org web address remain the same. But the mailing address has changed to: NAMHR, Ermire Building, 8th Floor, 1400 Locust Street, Pittsburgh, PA 15219.

The closing of Children’s Hospital at the University of Pittsburgh, where the NAMHR was previously housed, necessitated the move to the new location.

“Dr. Andrew Herlich, the new Chief of Anesthesiology at UPMC Mercy Hospital, and also an MH Hotline Consultant, was instrumental in negotiating a rent-free lease for the NAMHR at Mercy Hospital,” said Dr. Barbara Brandom, herself a Hotline Consultant and Director of the NAMHR.

The move to the location was completed the first week of February with about a week of prep time. In all, 50 boxes of Registry files were moved into the new location.

The Registry is an important repository of information related to malignant hyperthermia (MH); the information housed in the Registry provides valuable data for continued research of MH, as well as to improve our understanding of how to treat and diagnose this potentially fatal disease. The work of gathering this information is ongoing.

“I spent a number of hours this week speaking with families, three different ones, and there are two others calling on the phone – all of whom want to clarify their risk of MH,” said Dr. Brandom. “Some of these people are willing to have CHCTs, some of them had inconclusive genetic tests, some of them had relatives whose death certificates said they died from MH, and one had severe muscle injury.

“My highest priority, aside from protecting the patients that are my responsibility in the operating room, is following up with these families to get them a diagnosis, to get them connected to MHAUS to get MH identification bracelets, and to get their records into the NAMHR.”

If a person knows they have MH, or if they think they might have MH, then they may want to have their name in the Registry. This could happen when there is MH in the person’s family or when the individual has had an incident.

The Registry’s goal is to acquire, analyze and disseminate information regarding MH susceptibility to scientific investigators and physicians caring for MH-susceptible patients. The Registry data is used to conduct research into the pathophysiology, epidemiology, diagnosis and treatment of MH.

Dr. Brandom urges anyone whose name is included in the Registry to contact the Registry office at (888) 274-7899 to update their address if they have moved their home. A person’s participation in the NAMHR can help medical investigators in important ways.

Challenge Yourself!

Have you challenged yourself lately? How about challenging yourself with the “MH Case of the Month”? Visit www.mhaus.org and go to the Home or Professional’s Info Center pages and submit what you think is the correct way to proceed with these actual MH cases. Answers with narratives are provided for the previous month's cases.

Dr. Barbara Brandom at work at the new NAMHR location.
Help Available For A FREE MH-Susceptible Medical ID Tag

MHAUS has help available for the MH-susceptibles who have no insurance or cannot afford to purchase a medical ID tag. The Sandi Ida Glickstein Fund was established for the purpose of providing free ID tags for MH-susceptible patients who qualify. Since 2003, over 106 FREE ID Tags have been sent to MH-susceptible patients.

To take advantage of this program, please send us a letter indicating why you would like MHAUS to provide you with a complimentary ID tag.

The goal of the free ID tag program is to ensure the safety of MH-susceptibles during an emergency situation and to prevent a tragic outcome from MH.

For further information, please contact MHAUS at P.O. Box 1069, Sherburne, N.Y. 13460-1069; call 607-674-7901, or visit www.mhaus.org.

Have you visited us lately? Log on to www.mhaus.org to get the latest information on MH, order materials, post a message to the bulletin board or learn about the “Hotline Case of the Month.”

Slide Show Presentation For MH Risk Available

MHAUS offers a slide show kit (CD-ROM and slide format) with lecture notes on “Managing Malignant Hyperthermia Risk in Today’s Surgical Environment.” This presentation reviews the risk of MH and assesses current trends in the management of MH in the inpatient and outpatient settings. Two CME credits are available.

This is a valuable tool to assist in developing standard of care practice guidelines and algorithms to ensure patients at risk will have access to appropriate interventions for treating MH. The program is arranged so it can also be used as a self-study program to enhance individual knowledge of MH and the risks involved.

Cost is $165 plus shipping and handling for the slides and CD. Call 607-674-7901 or visit www.mhaus.org to order.

Yes! I want to support MHAUS in its campaign to prevent MH tragedies through better understanding, information and awareness.

A contribution of: $35 $50 $100 $250 $500 $1000 (President’s Ambassador) or (other amount) $__________, will help MHAUS serve the entire MH community.

Please print clearly:
Name: ______________________________________________________________________________
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☐ I am MH-Susceptible ☐ I am a Medical Professional

Please charge my ☐ Visa ☐ Mastercard ☐ Discover ☐ American Express
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THANKS! MHAUS is grateful for the financial support of the following State Societies of Anesthesiology: California, Connecticut, Florida, Illinois, Maine, Maryland, Michigan, Nevada, Ohio and Pennsylvania. Our appreciation also goes to the following state components of the American Society of PeriAnesthesia Nurses: Arkansas, Colorado, Delaware, DC, Illinois, Kansas, Maryland, Missouri, Nebraska, New Hampshire, New Mexico, North Carolina, Pennsylvania, Texas, Vermont and Wyoming. Call the MHAUS office to ask how your group can join their ranks!

Newsletter Archive
Looking for back issues of The Communicator or the MHAUS e-newsletter? You’ll find them archived on the MHAUS website. Simply visit www.mhaus.org and choose the “patient” or “medical professional” section, and then click “Communicator” in the left menu.

Dale Micalizzi Joins MHAUS Board of Directors
Dale Micalizzi has agreed to join the MHAUS Board of Directors. Mrs. Micalizzi has been a friend of MHAUS for several years, following the death of her son in what was supposed to be a straightforward anesthesia and surgery. Although the death was not linked to MH, she has become very involved in issues related to patient safety and compassionate treatment of patients and their families, particularly after an unexpected death.

“She has spoken at many national meetings on issues related to patient safety and medical errors and will bring to our board insights from other organizations that focus on such issues,” said MHAUS President Henry Rosenberg.

Upcoming Meetings Being Attended By MHAUS
The MHAUS staff will be attending a number of upcoming meetings across the country and in Canada. Meetings include: ASPAN in Washington, D.C. on April 20-22; ASCA in Nashville, TN on April 22-24; CAS (Canada) in Vancouver, BC on June 26-28; AANA in San Diego on August 9-11; MH Patient Mini-Conference in Oklahoma, OK on September 19; a second MH Patient Mini-Conference in Schenectady, NY on September 26; and the ASA in New Orleans on October 17-21. We hope to see you there!

Join The Cause!
Over 300 others have already joined the cause. You can, too, by visiting www.mhaus.org and clicking on the Facebook link.