MHAUS Honors Seven At Annual Recognition Reception

MHAUS honored seven recipients with five different awards at its annual Recognition Reception on October 20, 2008, during the ASA Annual Meeting in Orlando, Florida.

The Media Award recognized Patty Pensa, Staff Writer, Sun-Sentinel, Delray Beach, Florida, for her work to increase public awareness of the Malignant Hyperthermia Syndrome.

The Outstanding Dedication to MHAUS Award recognized Henry Rosenberg, MD, President of MHAUS and Director, Department of Medical Education and Clinical Research, Saint Barnabas Medical Center, Livingston, NJ, for his leadership, vision and dedication to the Malignant Hyperthermia Association of the United States.

Sandra Becker, MD, of the University of Witten, Department of Anesthesiology and Intensive Care Medicine Herdecke, Germany, received the Daniel Massik Award for her manuscript entitled “Comparison of Systemic Effects of 3,4-Methylenedioxymethamphetamine, of Ryanodex® Therapy and Uncoupling Protein 3 Expression in Malignant Hyperthermia Susceptible and Normal Swine”

A Special Recognition Award recognized Margaret Link, Marketing Specialist, P&G Pharmaceuticals, Inc, Mason, OH for her outstanding dedication and ongoing assistance to the growth of the Malignant Hyperthermia Association of the United States.

Mary Theroux, MD, of the DuPont Hospital for Children, Wilmington, DE and Richard McNeer, MD, of the University of Miami/Jackson Memorial Hospital, Miami, FL, were the co-recipients of the 2008 MH Hotline Partnership Award. This award recognizes special cases in which the 24/7 MH Hotline was used to solve MH cases in real time via the telephone or Internet.
MHAUS: The Year 2008 In Review

by Henry Rosenberg, MD

The fact that I am writing this message in December of 2008 and can tell you that we are an organization that continues to be sought out by thousands for advice and information is pretty remarkable given the fact that a wide variety of large, wealthy organizations are foundering or have gone under. Furthermore, we are planning new and innovative educational and patient service programs.

This success could not have happened without the support of hundreds of you who have contributed time and resources to MHAUS. I am referring to our members, our donors, our Board of Directors, Hotline consultants and Professional Advisory Council members and office staff. Everyone has busy lives these days, and for individuals such as our Hotline consultants and advisors to contribute their time and expertise to helping their peers and patients deal with MH and similar disorders is truly admirable. Not only do they share their expertise with those who are not as expert, but I can truly say that we learn from one another as well.

In addition to the ongoing activities of the organization, (i.e., publication of The Communicator, an E-newsletter, updated print information and posting new information on our web site, answering hundreds of calls from patients, health care providers and others, and exhibiting at about eight national medical meetings), there are several noteworthy events that have happened over the year. Here are a few:

In the spring of 2008, in response to the tragic death of Stephanie Kuleba from MH, Laura Landro, the medical writer of the Wall Street Journal wrote an article about outpatient anesthesia with an emphasis on MH. The article attracted a lot of attention and visits to our web site jumped significantly. Not only did the visits to the web site increase transiently, but the number of visits has continued at a high level. At present there are 2 million visits to our web site from all over the world! We truly are the place that people visit when they want insight about MH.

We spend a lot of time making the web site easy to use and a ready source of the latest information on MH for patients and health care providers. Slide shows, print material and a message center are all part of the site. I should also mention that our subsidiary organization, the Neuroleptic Malignant Syndrome Information Service (NMSIS) also supports a web site that contains valuable information. We recently posted a slide show on the serotonin syndrome prepared by Dr. Patricia Rosebush.

We will soon post a video of an actual muscle biopsy test done for MH susceptibility along with a demonstration of the laboratory findings when the test is performed. The video was recorded at the biopsy center at Wake Forest University, Bowman Gray School of Medicine with the help of Dr. Joe Tobin, Professor and Chair of the Department of Anesthesiology, and MHAUS Board Treasurer.

The web is only one way communication takes place in the modern world. We entered the social networking scene this past year with a “cause” page on Facebook. There are currently over 300 members of our cause. Regular postings of relevant information with commentaries enables rapid communication of the latest news of interest to the MH-susceptible and his/her family. Special thanks to Michael Wesolowski in our MHAUS office who works hard to keep the material fresh and relevant.

Another highlight of the year was a symposium in conjunction with the Society of Pediatric Anesthesiologists on the relation of MH to muscle diseases. Dr. Ron Litman was the principal

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2008 Annual MHAUS Recognition Award
Recipients
Congratulations to all!

(Pictured above) Sandra Becker, MD, of the University of Witten, Department of Anesthesiology and Intensive Care Medicine Herdecke, Germany, receives the Daniel Massik Award. (Middle right) Patty Pensa, Staff Writer, Sun-Sentinel, Delray Beach, Florida, receives the MHAUS Media Award. (Far right) Henry Rosenberg, MD, President MHAUS and Director, Department of Medical Education and Clinical Research, Saint Barnabas Medical Center, Livingston, NY, receives the Outstanding Dedication to MHAUS Award. (Below) Mary Theroux, MD, of the DuPont Hospital for Children, Wilmington, DE and Richard McNeer, MD, of the University of Miami/Jackson Memorial Hospital, Miami, FL, were the co-recipients of the 2008 MH Hotline Partnership Award. (Below right) Margaret Link, Marketing Specialist, P&G Pharmaceuticals, receives a Special Recognition Award for her outstanding dedication and ongoing assistance to the growth of MHAUS.
Hotline Consultants Discuss Updates At Annual Meeting

MHAUS held its annual Hotline Consultant Breakfast Meeting on October 20, 2008, during the ASA convention in Orlando, Florida. Attendees of the meeting included Drs. Henry Rosenberg, Joe Tobin, Barbara Brandom, Sheila Muldoon, Rich Kaplan, Jim Chapin, John Skoog, Mohanad Shukry, Andrew Herlich, Mary Theroux, Charles Watson and Kumar Belani.

Guests included Renee Krivosic, from France, Kevin Nolan, Klaus Thor, Linda Groom, Jonathan Katz and John Capacchione. MHAUS staff included Executive Director Dianne Daugherty, Hotline Coordinator Gloria Artist, and Scientific Officer Sharon Dirksen.

Dr. Rosenberg opened the meeting by announcing two recent hires by MHAUS. A consultant has been hired to help with core issues of the board and staff. Also, Michael Wesolowski has been hired as the PR/Projects Coordinator; he has created an MHAUS cause page on Facebook and has recruited over 150 people from all over the world.

Dr. Rosenberg invited attendees to stop by the MHAUS information booth during the ASA to view a video of the contracture test. With the help and the generosity of Dr. Tobin, Ms. Daugherty filmed 30 minutes (edited down to 5 minutes) of a biopsy. Narration will be added to the film with the goal of posting the video on the MHAUS website. A Spanish narration version was suggested by Dr. Herlich.

Attendees were asked for comments on a draft regarding the implications of MH in an outpatient setting. The draft was assembled by Ms. Daugherty following a round table discussion held last year following the genetic conference. The round table discussion was supported by a grant from P&G Pharmaceuticals.

Dr. Rosenberg also mentioned that MHAUS is in the process of converting the current Excel Hotline data into a searchable Access database. This should help improve efficiency.

**Scientific Advisory Update**

Dr. Dirksen discussed the Transfer of Care MH Protocol, which will develop guidelines in the event an MH episode occurs in an Ambulatory Surgery Center (ASC). The objective is to provide guidelines to transfer the patient from an ASC to a local hospital. Dr. Larach is leading the consensus development process.

Dr. Dirksen is also putting together a slide set to help doctors who are trying to gather information to assess risk in a patient and to determine whether to refer a patient for additional diagnostic testing relating to MH susceptibility (MHS). She has submitted the slide sets to Hotline consultants and received a number of comments. She will submit another draft shortly.

Dr. Dirksen reported the near completion of MHS informational booklets. The booklets are being developed in partnership with Genetic Alliance. “The point of the entire project is to get family members talking to each other about risks for MH,” Dr. Dirksen said. “This will be another great addition to the brochures that MHAUS currently has for patients and their families.”

**Summary of Hotline Activity**

Ms. Artist reported on the total number of calls to the Hotline and the number of AMRAs sent out from the MHAUS office. She also indicated that visits to the Case of the Month on the website continues to increase, but noted we could use a few more cases. She reported as well that visits to the President’s Blog are doing very well.

“The interesting thing is that when you look at the visits to the website, it’s overwhelming,” said Dr. Rosenberg.

Ms. Daugherty added, “The annual website page views is over two million, and, on a monthly basis, is well over 200,000.” The website appears to be growing on an almost daily basis, with 53% of the people viewing a page returning again within 24 hours.

“We get a lot of attention on the web and most of our orders come from the website,” said Dr. Rosenberg.

Ms. Daugherty reported that MHAUS has been receiving calls from ASCs and office-based facilities asking if there is one place they could go to get everything for an MH cart. Mr. Wesolowski has gathered information from the Drugs and Equipment brochure that lists everything needed on a cart along with its cost. Ms. Daugherty asked for input in determining whether this is a service MHAUS should provide. Dr. Herlich recommended using a company called Banyan International, which markets kits that have everything stuffed into them, as a model for MHAUS.

**Quality Assurance Update**

Dr. Watson suggested a periodic review of the forms used by the Hotline consultants along with possible changes to improve accuracy and efficiency. “It would be nice to see some automated hot buttons (on the Internet report form) for filling out forms that would immediately send key information to people,” he said. “This would make the lives of the Hotline consultants much easier. It is very troublesome to get a call while you are driving or in the middle...”
Continued from page 4

of the night and the next day when you try to put the information together, the results are very vague.”

Dr. Tobin commented that he’s found himself in the same situation as well. He suggested a 1-800 dictation number for Hotline consultants; after they receive a Hotline call, the could dial the 1-800 number and dictate the information from the Hotline call.

“I think that would be a good idea because we have all been in that situation and having the luxury of picking up the phone and dictating would be so simple,” said Dr. Rosenberg. He suggested the phone number go directly to a machine at the MHAUS office.

Dr. Watson also suggested that having an email address provided would be very helpful because the Hotline consultant could then send the caller a slightly edited version of what was said on the phone, as well as cover some items that weren’t discussed over the phone. He suggested some standard forms that the Hotline consultant could send would be helpful, too: AMRA, biopsy center list, and the cost for a biopsy.

Dr. Brandom said that having an email address provided would be very helpful because the Hotline consultant could then send the caller a slightly edited version of what was said on the phone, as well as cover some items that weren’t discussed over the phone. He suggested some standard forms that the Hotline consultant could send would be helpful, too: AMRA, biopsy center list, and the cost for a biopsy.

Dr. Brandom thanked the Hotline consultants for filling the AMRAs. The Registry received AMRAs on two MH deaths in 2008. Completed AMRAs allow for better understanding and research of MH. Indeed, the Registry has been the source for a number of publications about MH. Dr. Brandom invited people to submit ideas for publication. She said the Registry is willing to help with the process.

ASA Wellness Initiative Hotline
Dr. Jonathan Katz, Chair ASA Committee, explained the ASA Wellness Initiative Hotline for anesthesiologists in distress. The ASA Hotline would provide psychological counseling and lifestyle counseling. He asked for advice from MHAUS about running a Hotline. Dr. Rosenberg said that MHAUS is more than willing to share its information and knowledge with the ASA.

Mitochondrial CK Update
Drs. Muldoon and Brandom discussed their interest in mitochondrial CK/macro CK and its use as a prognostic marker in patients with muscle pain and cramping following an MH episode. Both said they would like to know more about these patients. They suggested that, perhaps, the leaky Ca channels from the MH event have not fully recovered in these patients, causing further muscle damage. There may also be increased production of nitrosylated products and free radicals, and a free radical scavenger may be appropriate to test as a treatment.

At this point, both Drs. Muldoon and Brandom would like the Hotline consultants to contact them if they have any MH patients (confirmed by probable episode, positive CHCT or causative mutation) who have these muscle problems.
Dr. Britt Helped Bring MH Awareness To Canada

Editor's Note: This is the fourth in a series of biographies related to those who played an important role in our understanding MH.

Her indefatigable labors in the quest for knowledge, basic and clinical, of malignant hyperthermia (MH) has made the name of Beverley Anne Britt synonymous in Canada with the understanding of the then-fatal syndrome.

Her numerous papers, her novel, creative ideas of testing and documentation, as well as her devoted interaction with MH patients and their families served to make the medical community of Canada well aware of all aspects of the syndrome. Moreover, in founding the MH Association of Canada, she literally put MH on the map of her county.

Dr. Britt was born in 1930 in Toronto, where she received her formal education. She interrupted her university studies to visit Europe in 1950, supporting herself in a factory job in Britain and later as a primary school teacher. Returning to the University of Toronto, she earned her MD degree in 1956. Following internship at St. Michael's Hospital in Toronto, Dr. Britt joined the Royal Canadian Air Force as a Medical Officer and served in Goose Bay, Labrador, from 1957 to 1961.

Entering the Diploma Course in Anesthesia of the Faculty of Medicine at the University of Toronto (UT), she received her diploma in 1964. In 1965, she became a Fellow of the Royal College of Physicians and Surgeons of Canada. The following year she was appointed a Clinical Teacher and Research Fellow at UT in the Departments of Anesthesiology and Pharmacology, as well as becoming a staff anesthetist and assistant professor of anesthesia at the Toronto General Hospital.

Her investigation of malignant hyperthermia, much of it in association with Dr. Werner Kalow, began in 1966 and continued until her retirement in 1996.

The development by Drs. Britt and Kalow of the caffeine contracture test (Lancet 1970; 2:245-247) had important implications in that it showed that caffeine in large amounts can cause muscles to contract and is as reliable as halothane as a test to indicate susceptibility to MH. Her research was conducted on pigs' muscle fibers placed in a contraction chamber as well as on muscle biopsies of human patients and their relatives.

Dr. Britt has been especially renowned for the wealth of data she and her associates collected on genetic aspects of the disorder and on autosomal modes of transmission. She recognized that MH is a true pharmacogenetic disorder in that both an inherited predisposition and a triggering agent are necessary to induce the acute MH crisis. She also charted the mortality associated with various inhalational anesthetic agents as well as the rigidity associated with each agent.

To further bring attention to the syndrome, Dr. Britt along with Drs. Kalow and RA Gordon (renowned for his administrative and educational contributions to MH worldwide), organized the first International Symposium on Malignant Hyperthermia in Toronto in May 1971.

In order to devote time and manpower to her research, Dr. Britt established a special MH Investigation Unit of the Department of Anesthesiology at UT. Exhaustive surveys on patients and their families were conducted throughout North America and extended into Europe to demonstrate the hereditary nature of this error of muscle metabolism.

Moreover, she was able to interact with the many patients and their families who were tested at the clinic, giving her firsthand knowledge of the varying aspects of MH episodes and also ways to forestall an MH crisis. This unit continues to identify and counsel patients as well as to uncover new clues to the nature of MH itself.

A gala retirement dinner was held in 1996 in Toronto to celebrate Dr. Britt's 30 years of research into MH. She has since retired to a cottage in Wales, a place that provided an occasional respite from the frantic pace of her activities to further the knowledge of this complex and still lethal syndrome.

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.”
Deadline Nears For Promising New Investigators Scholarships

The Neuroleptic Malignant Syndrome Information Service (NMSIS) is pleased to announce a competition to recognize promising new investigators based on a scholarly paper addressing “New insights on psychotropic drug safety and side effects.”

A subsidiary of the Malignant Hyperthermia Association of the United States and under the leadership of Vice-President and Director Stan Caroff, MD, the mission of NMSIS is to advance pharmacotherapy and patient safety.

NMSIS offers two travel scholarships to promote education and research by early career psychiatrists. Two prizes of $2000 and $1000 will be awarded toward travel costs to attend the American Psychiatric Association Meeting in San Francisco, CA, in May 2009, where the scholarships will be presented.

Papers should address specific issues related to the scholarship theme and be no longer than 15 double-spaced typed pages in length. Literature reviews, case reports, or original studies that are not in press or published are acceptable. Primary author must be a student, resident or fellow. Papers will be judged on originally, scholarship, relevance and methodology.

To participate, papers and curriculum vitae of the primary author must be submitted by February 6, 2009 to Mr. Michael Wesolowski, 11 East State, Sherburne, NY 13460, fax 607-674-7910, or via email to michael@mhaus.org.

Winners will be announced by March 6, 2009.

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.
MH Hotline Activity – First Quarter 2008

by Charlie Watson, M.D

The Hotline Consultants (HLCs) reported 75 consultations and questions from January to March 2008. Calls came from more than 40 states and Canada. Consultants contributing included Dr.'s Brandom, Chapin, Gronert, Melton, Miller, Parness, Rosenbaum, Rosenberg, Shukry, Tobin, Watson, Weginiski, and Wong. The majority of callers were anesthesia professionals from hospitals and ambulatory centers. Other callers included a plastic surgeon, dentist, three CRNAs, a paramedic, and an emergency medicine physician.

Muscle disorders and MH

Of 25 questions raised by 23 anesthesiologists, a paramedic, and a registered nurse from an ICU, ten focused on MH risk in patients with other neuromuscular diseases or when other members of the family had MH or MH-like events. McArdle’s disease, spinal muscular atrophy, muscular dystrophy, myasthenia are conditions that have not been shown to be associated with MH susceptibility (MHS). One caller, an anesthesiologist who runs an anesthesia test preparation program for anesthesiologists, used the Hotline as a source reference for clarifying questions about unrelated muscle diseases.

Masseter muscle rigidity (MMR), an unexpected contraction of the jaw muscles during anesthesia or after administration of muscle relaxant drugs, although, is associated with MH susceptibility (MHS). Consultants recommend that patients whose close relatives have experienced MH or masseter spasm should be treated as MHS until proven otherwise. Also, in families where an individual has experienced an MH crisis (MHC), the fact that another family member has had an uneventful anesthetic, does not mean that that person is not at risk for MH.

Post Op Fever

Eight questions that HLCs felt were not due to MH were related to fever during or after anesthesia. Two patients who had fever 2 and 5 hours postoperatively with metabolic changes and increases in metabolism were treated with dantrolene in hopes it would reverse MH-like symptoms in an ICU setting. One patient was shown to have an infection, but the other was referred to a biopsy center for muscle study and genetic studies.

Post-operative fever noted in the Post-Anesthetic Care Unit, another Critical Care Unit, or in Emergency Department accounted for 25 consultations. Most were not MH, rather they were bowel infection, pre-operative upper respiratory infection, pneumonia, and unknown viral illness. When the HLC or the anesthesia team had confirmatory evidence suggestive of MH or an MH-like episode, close monitoring and dantrolene therapy were recommended, often with detailed advice for the caller about dantrolene dosing over time and the timing of specific monitoring tests.

The Fetus of an MH father and non-MH mother

A very interesting question and two urgent HLC consultations were about MH risk of a baby whose father had experienced an MHC. When the mother is not known to be MHS, but the father is MHS or possibly MHS, could anesthesia for Caesarian Section (C-section) trigger an MHC in the baby?

We could find no fetal cases of a confirmed MHC in the world literature, although very young infants (3 or more weeks old) have experienced an MHC. Regional anesthesia without MH triggering agents is the most common anesthetic for urgent and scheduled deliveries by C-section. We know that inhalational agents that trigger MHC do pass from maternal to fetal blood via the placenta, although most likely at very low levels. Discussion has continued following these questions on the HLC internet chat group. An expert consensus has been reached. HLCs and MH specialists from abroad believe that, when spinal or epidural anesthesia is contraindicated or there is a sudden, emergency need for general anesthesia, anesthesia caregivers should plan a safe, MH trigger-free anesthetic. Intravenous anesthetics, opioids, sedatives, and nitrous oxide can be given as an alternative to other potent inhalational agents. Succinylcholine, the muscle relaxant most commonly used to enable insertion of a breathing tube for the mother’s safety during C-section under general anesthesia, is a potent MH trigger. Although succinylcholine is more convenient because it acts very quickly and wears off rapidly, other relaxants given in large doses work almost as quickly.

MH Crises. Two Deaths

Four callers that suspected MH crisis reported remarkable jaw muscle rigidity during anesthesia that caused them to cancel surgery or convert to a non-triggering anesthetic technique. HLCs discussed the best means of following such patients for MH or MH-like events with these callers and recommended close monitoring for muscle breakdown.

Two tragic deaths related almost certainly to MH were reported. Although dantrolene was given to both patients, its possible that the MHC was so far advanced when recognized, that cardiac arrest was imminent. In one case, an older individual demonstrated increasing carbon dioxide levels and tachycardia in the prone position during back surgery. His heart stopped while the anesthesiologist spoke with...
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the HLC and it seems likely that a prior history of heart attack and the patient’s limited cardiovascular reserve contributed to his death.

A plastic surgeon called the MH Hotline about an 18-year-old who was undergoing plastic surgery for breast augmentation. The anesthesiologist gave a small dose of succinylcholine to relax her muscles for a part of the procedure, but stiffness was noted instead. MH was then suspected because of increasing rigidity, fever and tachycardia. Although the surgeon and anesthesiologist treated this young woman with dantrolene, she became very unstable and her heart stopped in the surgeon’s office and in the ambulance during transport to the hospital. The HLC followed the episode as closely as possible and spoke with several physicians about the young woman’s situation. Despite intensive care with continued dantrolene treatment and ongoing life support, the teenager died. This MH event has generated interest. This teen’s death was reported in both local and national media, internet, and televised press. Because of this and earlier cases from ambulatory and office surgery centers, MHAUS experts together with representatives of the Ambulatory Surgery Center Association and the Emergency Medicine community, are developing guidelines for identification, resuscitation, transport, and late management of individuals who develop an MHC in ambulatory surgery centers.

Summary and Conclusions

Review of these 75 calls and their follow-up discussion shows some trends. More calls than ever before reveal that follow-up discussion, information sharing, and referral benefit from e-mail and other electronic media because of the ease of dissemination of information. Electronic communication helps the HLCs avoid the missed phone connections that often plague such discussions between busy practitioners over time and across distance in North America.

MHAUS has put useful resources on the internet, which both health care professionals and lay persons consult. More recently this includes the “Case of the Month”, Dr. Rosenberg’s podcasts, and slide presentations that address issues like genetic testing, identification and management of MH-like events, and MH, itself. To supplement this information, MHAUS, together with HLCs, is putting together ready guides for electronic communication about the most common post-event monitoring and management issues: for example, how to recognize and manage muscle breakdown that takes place during an MHC or following MMR seen in patients with muscular dystrophy.

HLCs often refer callers to the diagnostic and management information that exists on the MHAUS website, but the need for an MH Hotline continues. Some callers simply want to speak with experienced professionals so they can discuss their thoughts and plans for care. Some seek advice as they are preparing for departmental education or the preparation of MH protocols. Others want to be certain that they aren’t missing something. Still, many physicians and other health care professionals who call seem to be unaware of important steps in diagnosis, management, monitoring and follow up care of patients who have an MHC or MH-like events. Several HLCs made comments like, “there’s still work to be done” as part of their report conclusions in the first part of 2008.

Meet This Issue’s Hotline Consultant

Charles B. Watson, MD, FCCM, graduated from the University of Maryland’s School of Medicine in Baltimore, MD, and completed anesthesiology residency training at the Penn State University’s MH Hershey Medical Center and in the US Navy in Portsmouth, VA, and Bethesda, MD, with post-graduate fellowships in pediatric anesthesia and critical care medicine at George Washington University, in Washington, DC.

Following service on the faculty of the US University of the Health Sciences and as Director of CCM, then Cardiac Anesthesia, and, finally, Assistant Department Chairman of the Anesthesiology Department at the National Naval Medical Center, in Bethesda, Dr. Watson joined the faculty of the University of North Carolina where he worked as an anesthesiologist and intensivist at the NC Memorial Hospital and served as director of the Critical Care Division.

During his time at both institutions, Dr. Watson managed patients with either the MH crisis or MH susceptibility and became a local consultant for MHS patients and their families. This interest continued when he entered the private practice of Anesthesia and Critical Care in Bridgeport, CT, in 1986, and accepted a clinical faculty appointment at the University of CT in Farmington. He joined the MH Hotline when it was established in the 80’s and has served as a consultant, occasional contributor to The Communicator, a regional speaker on MH-related topics, a member of the MH Hotline Q/A Committee and, more recently, chair of that committee.

Dr. Watson has been the Chairman, Department of Anesthesia, Bridgeport Hospital since 1989 and presently serves as Deputy Surgeon-In-Chief of that institution, which belongs to the Yale-New Haven Health Network. He and his wife, Masha, live in Easton, CT, and have three adult children.
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organizer of the meeting which featured expert speakers from the MH and the Neurology community. It was a packed house. At present, the presentations are under review in the editorial offices of Anesthesia and Analgesia, an international anesthesia journal. It is hoped that the symposium will be in print in a few months.

At the American Society of Anesthesiologists annual meeting there were about 20 abstracts related to MH and a variety of other presentations. Many derived from data from the North American MH Registry of MHAUS. Two important publications appeared in the journal Anesthesiology based on data from the Registry. One related to cardiac arrest and mortality from MH over the years, the other related to post-operative MH. Speaking of the Registry, it will soon relocate from Children’s Hospital of Pittsburgh to Mercy Hospital in Pittsburgh. Both are part of the University of Pittsburgh Medical Center and the oversight of the Registry and its operations will continue as they are at present, with Dr Barbara Brandom as the Director. The reason for the move relates to the relocation of the Children’s Hospital to a new address and the need to reconfigure space in the new facility. Our sincere thanks to the administration of Mercy Hospital and Dr. Andy Herlich, Chairman of the Department of Anesthesia, for coming to our rescue.

In response to several deaths related to MH where the episode started outside a hospital surgical facility, MHAUS has been working with the Ambulatory Surgery Center Foundation to create a transfer of care protocol. It is critically important that all those caring for patients who sustain an MH crisis in an ambulatory surgery center are skilled in the management MH and have mechanisms in place to transfer the care of the patient to the hospital setting. This initiative is being headed by Dr. Marilyn Larach and our scientific officer, Sharon Dirksen. Anesthesiologists, Emergency Medicine physicians, CRNAs, SAMBA representation, and Emergency Medical Technicians are involved in the effort.

In September of 2007 a meeting was held to develop guidelines for preparation, recognition and management of MH in an ambulatory surgery setting. The consensus document is now completed and will be made available to the public in the next few months.

We also sponsor programs to bring the MH experts to hospitals and meetings of health care professionals. Our Speakers Bureau has funded 13 such talks by experts in 2008. In addition, a patient/professional MH conference was held in Florida in September and was attended by over 100 people.

Another important event in 2008 was the sale of Dantrium® (dantrolene) from Procter and Gamble Pharmaceutical to two companies, JHP Pharma in New Jersey and SPE Pharma in Holland. Procter and Gamble was the sole manufacturer and distributor of dantrolene since 1979 until 2007, when a generic version was introduced by US World Meds. Now, the Dantrium product will be made and distributed by JHP in the US and several other countries with SPE Pharma distributing the product in Europe. Fortunately, this transfer of ownership seems to have taken place seamlessly and the 30 year anniversary of the Dantrium Brand will occur in September of 2009.

Testing for MH susceptibility is in a state of rapid change. The muscle biopsy contracture test is now offered by only four centers in the US and two in Canada. One biopsy center, Thomas Jefferson in Philadelphia, ceased operations in the fall.

Molecular genetic testing is offered commercially by two centers and one research center in the US. Although molecular genetic testing cannot replace the gold standard contracture test, for some situations, such as families where a mutation has been found, genetic testing can be extremely valuable and obviate the necessity for a biopsy. It is hoped that research in the genetics of MH by centers such as the one at Uniformed Services University in Bethesda, MD will increase the accuracy of genetic testing through ongoing research.

Those of us connected with MHAUS and NMSIS and the North American MH Registry are pleased to contribute to the health and well being of MH patients and their families and to help the clinicians who are caring for them. However, we realize that our work is far from over. We need to make sure that all personnel who care for MH-susceptibles and their families are familiar with the syndrome and its special problems for those who undergo molecular genetic testing and how the test results should be interpreted. We also are aware that the growth of surgery in the ambulatory or office-based setting poses special problems for those who are MH-susceptible or experience an MH crisis in such centers.

In my next blog I will begin to outline some of the new programs that we are planning for the coming year to meet those needs. You can view the blog by visiting the MHAUS web site at www.mhaus.org/ presidentsblog. Special thanks to the MHAUS staff. Without them there would be no MHAUS: Dianne Daugherty, Executive Director, Gloria Artist, Nicole Viera, Fay Kellogg, Michael Wesolowski and Sharon Dirksen, our Scientific Officer.
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.

Join The Cause!

Have you visited us online lately? Log on to www.mhaus.org and learn how you can join the “cause page” on Facebook. A link to the MHAUS Cause Page is found on the home page.

Also, keep checking back. A slide presentation will be available soon on the MHAUS web site concerning diagnostic testing for MH; the presentation addresses issues of muscle biopsy and genetic testing for MH.

European Malignant Hyperthermia Group Meeting Scheduled For April 14-16

The European Malignant Hyperthermia Group 2009 Annual Meeting is scheduled for Victoria, Australia, April 14-16.

The meeting will aim to showcase recent MH research in Australia and New Zealand and to identify potential areas of collaboration between MH centres around the world.

Guest speakers include Drs. Michael Denborough and Dr. Jim Villiers, along with local speakers Mark Davis, PhD, Margaret Perry, FANZCA, Kathryn Stowell, PhD, Andrew Bjorksten, PhD, Robyn Gillies, FANZCA, Neil Pollock, FANZCA, and Neil Street, FANZCA.

For registration and accommodation information, visit the EMHG website at www.emhg.org.

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: ______________________________________________________________________________
Address: ____________________________________________________________________________
City: ____________________ State: _____________ Zip: _________________ Phone: __________________________ E-mail: _________________________

❑ I am MH-Susceptible ❑ I am a Medical Professional

Please charge my ❑ Visa ❑ Mastercard ❑ Discover ❑ American Express

Name on card: _________________________________________________________________
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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!

MHAUS Welcomes Deanna Steele to PAC
Deanna Steele has joined the MHAUS Professional Advisory Council (PAC). Ms. Steele is a genetic counselor with Magee’s Center for Medical Genetics at the University of Pittsburgh Medical Center. Ms. Steele has been a genetic counselor for 22 years and has counseled a number of patients interested in MH testing. Her experience will be a valuable resource for PAC and MHAUS.

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 follow the links.

Anesthesiology Publishes “Postoperative Malignant Hyperthermia”
Anesthesiology has published “Postoperative Malignant Hyperthermia: An Analysis of Cases from the North American Malignant Hyperthermia Registry” in its November 2008 issue. Authors of the study were Ronald Litman, D.O., Christopher D. Flood, M.D., Richard Kaplan, M.D., Yung Ly Kim, M.S., Joseph Tobin, M.D., F.A.A.P., F.C.C.M. The authors identified postoperative MH in 10 subjects. All received volatile agents and five also received succinylcholine. All demonstrated signs characteristic of acute MH, including generalized rigidity, hypercapnia and/or tachypnea, tachycardia, and hyperthermia. No subject demonstrated hyperthermia as the presenting sign. The latency period between the anesthesia finish time and the onset of a sign indicative of acute MH ranged from zero to 40 minutes.