

MHAUS Board of Directors Meeting Minutes

Thursday January 14, 2021

Zoom Online Meeting

Board Present: M. Betts (MB), J. Cahn (JC), S. Caroff (SC), C. Keller (CK), D. Mashman (DM), M. Poler (MP), H. Rosenberg (HR), J. Sumanis (JS), J. Tobin (JT), R. Vladutiu (RV), S. Watt (SW)

MHAUS Staff: G. Artist (GA), D. Daugherty (DD), T. Roalef (TR)

Guest: Amy Gunnett (AG) – North American MH Registry (NAMHR)

Board Absent: C. Mercer (CM), S. Napolitano (SN), T. Passig (TP), S. Riazzi (SR)

JT welcomed board and asked DD to discuss the slate of officer ballot results

- DD stated new officers as follows” JT – President, SW Vice President and Treasurer, and SN Secretary

JT asked that HR talk a bit about his journey as President

- HR discussed the history of MHAUS, his role, the growth of the organization, and the advances in genetics
- HR stated that he would like to stay on the Board of Directors as “President Emeritus”
- JT and Board thanked HR for his many years of service and work with genetics and board diversity

MOTION: JT moved to accept August 2020 Meeting Minutes; HR seconded the motion. Vote taken; motion passed.

DD gave financial and administrative update

- DD explained the current COVID19 pandemic has had a negative impact on MHAUS financials but we are seeing a rise again
- As of November 2020, there is a deficit of approximately \$48,500; in December it improved to -\$27,642.39
- HR asked what led to the decrease in deficit – DD stated fewer orders; stock increases remain a large contributor

CK gave Patient Liaison Committee update

- CK discussed the main goals of the PLC to be to provide a safe place for patients to find support and ask questions, promote stronger connections between patients and MHAUS, and promote more patient membership and participation in the Registry
- CK discussed the possibility of setting up a rotational schedule for the PLC to address incoming patient inquiries on the MHAUS website. Lydia Friedman is currently tasked with this. CK to work with TR and GA to come up with schedule
- JT suggest an older version of the Communicator be sent to patients asking questions – DD agreed

JT gave investment committee update

- JT reported that the S&P and metrics have recovered well from the rocky period earlier in 2020 now with double digit returns. MHAUS dropped Boeing stock and switched the funds to dividend stocks.
- JT stated that the committee is very pleased with Leigh Baldwin’s advice and will be meeting with him in near future

DD gave the Administrative Update

- GA is unsure if the August Planning Meeting will be held in-person or virtual due to the current pandemic
- GA suggested August 13th and 14th or August 21st and 22nd as potential dates for planning meeting. JT asked that GA send out these proposed dates to the Board to see which works best for the group
- DD welcomed new Board Member, Dr. Mark Poler, to the MHAUS Board
- DD reported the MH Hotline data transfer process into RedCap is complete and the NAMHR worked with Dr. Pinyavat to implement surveys to callers and consultants. AG and Registry team have been extremely involved in the process.
- NMS and TD webcasts are now posted to the NMSIS website, providing updated content
- Elaina and DD working to schedule yearly audit with Cwynar & Company in early 2021
- DD discussed her recent hip surgeries. She stated that she is recovering and should be back in the office very soon
- Virtual MH Mock Drill Check is in the works and hope to have a beta event scheduled for February 2021
- DD reported various fundraising efforts are going well, while some did not return as expected – such as the Year End Appeal

- Awaiting response from SN regarding the Health Scholars contract – DD to push to get input. JC asked if revenue can be expected from Health Scholars and DD replied maybe not this year as the contract is not moving along as quickly as expected, but anticipated for later in year or early in next fiscal year.
- DD working with Medic Alert and SN to complete negotiations on new agreement.
- Succession planning has been a top priority – Ad to be placed on various employment websites when DD returns to office

GA gave MH Hotline Report

- There are two new MH Hotline Consultants – Dr. Christopher Edwards and Dr. Christopher Heine
- New recruit – Sandra Gonzales (UFL) has been approved to be a hotline consultant – beginning mentor period with Dr. Erica Sivak
- GA is working to recruit new consultants as there are only 24 active HLCs currently; TP will work on letters to present HLCs for new HLC suggestions
- GA and HR reported the calls to the hotline seem to have returned to pre-pandemic numbers.
- There are approximately 2 COVID-related calls/week (about 20% of total calls)

TR gave Projects Report:

- TR reported that social media attention and engagement is decreasing as well as website traffic as a result of the ongoing pandemic
- TR discussed the success and increased revenue from the webinar series. JC suggested hosting a webinar about COVID and MH – Board agreed – TR to ask Dr. Pinyavat to be a speaker
- HR suggested reaching out to Mike Greenberg from Eagle about the discussion that HR contributed to their REACH program about malignant hyperthermia and dantrolene as well as Mr. Greenberg's other ideas about popularizing the use of Ryanodex

DM gave Education Committee Update

- DM discussed the goals and objectives for the committee (see attached report) and thanked JC for her meeting coordination work
- DM reviewed the current projects of the committee to be reviewing the healthcare professionals tab on the MHAUS website and developing an education committee project evaluation tool (attached)
- The MHAUS website is currently in review by committee members to analyze where information should be updated. Committee will report back to Board with timeline and recommendations following the Feb. 2021 committee meeting
- DM asked if members from outside the Board of Directors would be allowed to participate in the committee, JT said yes. Committee to consider recruitment of diverse committee members
- JT stated that the healthcare professionals' section of the website is the most important and it is the most popular according to website analytics – MHAUS is not in a place at the moment for any financial commitment to bring in outside website developer
- MP mentioned Square Space as a potential website host to save costs- DD stated most website revisions are done by staff – Marc Funaro is contracted to house the MHAUS server and provide security
- SW discussed summer internship opportunities to work with Education Committee and Registry as it could help MHAUS save funds. DD agreed that we should look into this
- MP asked if we reached out to MOCA Minutes? JT agreed this would be a good idea.
- DM discussed the Trivia Tuesday emails sent out by staff every Tuesday to also include clinical information. HR agreed that the topics should be diversified to reach more people. Education Committee to discuss during next meeting and will report back to the board.

HR gave genetics update

- HR is part of an expert panel with ClinGen about genetics for MH susceptible individuals. The panel meets about once or twice per month and discusses variants that are causative to MH and classifies them into their pathogenicity through a scoring system and internal debate. A paper is being written and will be published in the near future.
- HR stated that this may cause a major shift in testing in MH
- HR suggested that MB talk with Jennifer Johnston from the NIH to compare notes

SC gave NMS update

- SC stated that the Osmotica Grant was received and used for the NMS and Tardive Dyskinesia webcasts now on the website
- SC working with Dr. Charles Watson and HR about MH-like drug induced syndromes, SC has a publication regarding this topic set to come out this year in a psychiatric publication
- SC to work with MB to research RYR1 mutations that may underline MH-like syndromes
- SC discussed the \$10K research grant that was received from Eagle Pharmaceuticals to partially fund VA research regarding the number of veterans who received dantrolene IV during a ten-year period. SC stated that preliminary raw data may be available in early Feb 2021. In 1-2 months, he hopes to report back and then pursue publication of the results of the study.
- MP to work with SC to compare notes about dantrolene used as fever reduction as there is much use of dantrolene to control fevers

DD and JT discussed succession planning

- DD mentioned the advertisement for her position is complete and set to be posted to various recruiting websites when she returns to office – all responses will be shared with the Interview Committee along with CV's and background information
- JT mentioned he has board members interested in assisting on Interview Committee; plans to hold interviews online

AG gave NAMHR report

- AG stated 92% of files sent from old registry have been converted
- 130 new patient enrollments since Dec. 2017
- AG discussed a study being completed by Erica regarding the evolving use of dantrolene – determined Ryanodex use is increased
- AG presented a rough draft advertisement card that offers information about MH – still in its infancy. CK asked that non-anesthetic triggers be added. RV asked that statin-induced information also be added

DD presented the FY 20/21 proposed budget and operating plan

- JT asked DD to send asset growth chart to Board for review
- No opposition to proposed budget and/or operating plan

MOTION: CK moved to accept 2020/2021 Budget and Operating Plan; JS seconded the motion. Vote taken; motion passed.

SW gave St. Jude update

- St. Jude has begun genetic testing on 3 markers for MH susceptibility
- St. Jude would like to partner with MHAUS to allow shared data and bring MH genetic counseling to patients
- SW stated that there are further ideas in the works as well. This is a good opportunity to build a databank.
- JT stated that he supports continuing to work with St. Jude and would be willing to complete a confidentiality disclosure to move forward.

Meeting ended at 2:10 pm (Eastern Time).

Respectfully submitted by Tina Roalef and Dianne Daugherty

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MOTIONS PASSED

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TO DO LIST

Dianne Daugherty

Work with SN to get contracts reviewed and returned for both MedicAlert and Health Scholars
Executive Director job opening ad out on various websites for recruitment
Look into summer internship opportunities to assist with admin tasks and other areas within MHAUS
Send asset growth charts to Board for review
Coordinate audit completion with Cwynar and Company

Education Committee

Committee to develop clinical questions for Trivia Tuesday email campaign
Committee to review the Healthcare Professionals tab on MHAUS website and develop report of suggestions to improve
Committee to recruit members for the committee who are not MHAUS Board members

Gloria Artist

Send out proposed dates to Board of Directors for August Planning Meeting 2021

Joe Tobin

Set next Investment Committee call

Megan Betts

Reach out to Jennifer Johnston from NIH to compare notes about ClinGen

Patient Liaison Committee

CK to work with TR and GA at MHAUS to develop a calendar for online inquiries
CK to work with TR to develop a follow up process for inquirers to possibly include an older version of The Communicator

Stan Caroff

Share preliminary raw data from VA research with board in February, if possible
Work with MB for RYR1 research for MH-like syndromes
Work with MP regarding dantrolene used for fever reduction

Stacey Watt

Continue work with St. Jude to develop a partnership

Tina Roalef

TR to work on COVID webinar for Feb. – reach out to Teeda Pinyavat as potential speaker
TR to reach out to Mike Greenberg from Eagle Pharm to discuss HR's talk and other avenues for Ryanodex popularization