

## August 8-9, 2020 Strategic Planning Meeting Minutes

### Day 1 – August 8, 2020

*Board Attendees:* HRosenberg (HR), SCaroff (SC), BDenholm (BD), SNeapolitano (SN). JTobin (JT), JCahn (JC), CKeller (CK), DMashman (DM), MMcMinn (MM), CMercer (CM), TPassig (TP), SRhazi (SR), JSumanis (JS), SWatt (SW)  
*Board Absent:* GVladutiu *Staff:* GArtist (GA), DDaugherty (DD), TRoalef (TR), FViera (FV)  
*Guests:* LBiesecker, AGunnett (AG), (LB), BKamsoke (BK), NGravenstein (NG), HLC Chair, TPinyavat (TP) MPoler (MP), CSandau (CS)

HR opened the meeting with thanks to those attending for taking their time to participate and share insights. SN noted it is very interesting being part of a global organization to see more people working creatively with Zoom. NG noted his chastened residents at UFL are back at work.

**HR asked for approval of the Minutes from the April 24, 2020 Board Meeting. All approved.**

DD shared the financial status: we experienced a reduction in orders during initial COVID pandemic, but they are now increasing. We received nearly \$47K from the PPP program which helped the bottom line a lot. Still had to take \$10K from the Investments (Walker Fund) to assure payroll and other expenses were met. TP noted Joint Commission held visits during COVID and are now completing them. This should help increase sales.

**DD requested, with the current financial situation, that the \$6996 (10% of 2018/2019 Net Income) be put on hold until later in this fiscal year to a time when we can, hopefully, make up the deficit from COVID. Board agreed.**

**Molecular Genetics:** HR noted he invited Les Biesecker to the meeting and asked LB to share his genetics progress and mentioned the article written by LB and HR. LB and MP were asked to comment on article. LB noted it is exciting to work on the article and we need to bring MH to the forefront. Can do functional assays on 10's of 1,00's amino acid change in RYR1 to obtain comprehensive results to allow MH genetics before it happens versus after to eliminate MH deaths. SW asked about whether this can be done in newborns? LB noted there is work going on to determine how to do next gen sequencing for newborn screening and add to biochemical screen. It is some way off, but important to assure a way to keep the genetics with patient records. MM is working on a manuscript (25% complete). HR noted Geisinger has strong electronic medical records that can be share with MDs. CK asked about follow up with MHS patients and how MH can affect them outside surgery? HR shared the challenge of Exertional Heatstroke and Rhabdo connection. Clarification is not clear and is challenge for future. MP noted due to nature of problem, much work is on the individual review of chart records; MHS noted in charts is very helpful. HR stated the role of genetic counselors is very helpful as they focus on communication with patients. We are glad for MM's input on the board. MM noted challenge that not all institutions have genetic counselors available. Cost of sequencing for research is \$260-275, but public cost is hard to say; few thousand dollars to eight thousand. Some companies, like Invitae, offer large panels for \$250 or so if self-pay. HR noted MHAUS should be involved. LB talked a bit about CRISPR technology. DM noted the MH Incidence Study (grant from MHAUS) is for incidence and analysis; an addendum would be needed to look at the genetic side.

**Real Estate:** JC asked about 501c3 limitations on this possibility? If done, would revenue be taxable? SN will talk to lawyers who are involved in this area about this and report back. This topic was tabled.

**President's Update:** Scientific Conference will not be held in January 2021 due to COVID uncertainty. We need to get patients more involved in MHAUS. Good progress made at Registry in FL. Molecular genetics is important. Francis Collins (NIH) is keynote speaker at ASA and may be speaking about MH and molecular genetic testing. HR believes there should be more patients asking for testing and MHAUS PAC will be called on for advice. When the paper is published in Anesthesiology, we should talk with the President of ASA about the need for genetic testing. JT noted we may propose MH testing, but other larger issues may also push for their disorder. HR suggested DM reach out to LB to be involved in her study. DM sees that as a next step as it is now important to get the data definition as a foundation. HR noted Eagle's FDA approval is to be decided on Sunday and if approved, this could be a good thing for us. SN noted if approved, could see it in all high-level sports and will pick up momentum. It is an opportunity to broaden our scope and align with right groups. We are repository for knowledge in this area and have

domain/research. HR noted this is of military interest. The Registry collects data and will work with LB on genetic testing. HR will work with Scott Tariff (Eagle CEO) about working together. HR talked about Twitch, the Amazon gaming site. JT noted before we put time into this, we need to know about other charities who have benefited from this avenue. HR noted St. Jude raised funds from this. JS noted we may not want to spread ourselves too thin to do this. JT asked if income is from players or selling ads? TR shared those involved pledge funds for number of hours for a person to play a game, like a virtual gaming event. Topic was tabled.

**Fundraiser Discussion:** JS noted this is a specialty area and should we invest in a fundraiser to take it on? DD noted in the past, we did hire someone to do this for us with no results. Could we fundraise with facilities as part of fundraising base? Certify them as MH prepared facility? JC noted every OR knows about MH – target is office-based surgicenters and ASCs. DM suggested connection with APSF to achieve larger overall certification. HR suggested another option may be support of genetic testing for MH? It was noted we could consider becoming a *Center for Excellence*. Need to know more about the process. JS noted we could certify someone as an MH resource if we were a Center for Excellence. JC noted we could offer a fellowship for someone who will study MH. JC noted the OR Educators need to assure MH training is done, TP noted they are involved for Joint Commission reviews, JS suggested simulations could use a camera and Zoom to share with wider audience. We could work with Educators and help them set this up and then debrief as to how to improve the process.

**The Communicator:** BK shared the newsletter process and asked for ideas for articles or for anyone who would like to write an article. Concern brought up by JS about the ease of finding newsletters and what topics are in each; HR noted we could produce an index of 10-20 recent issues. JC asked what is always included, like hotline report synopsis. BK noted we haven't had synopsis for a while. JC asked for membership breakout to determine topics of interest for the largest group of readers.

JC asked if we could target the types of nurse members and promote to them? TP noted she has lectured on MH to ASPAN and the current President is interested in MH. We were going to put on an MH simulation at the 2021 meeting, but tabled due to COVID. She will continue to work on this effort for a future ASPAN meeting.

**NMSIS:** SC shared the background of NMSIS for the new members. He is working on IRB approval, hopefully by the end of the month, to move forward with feasibility pilot data from VA national database for administration of IV dantrolene. He also garnered \$2K from Osmotica for 2 webcasts on the NMSIS website. First on tardive dyskinesia completed and will be placed next week; second on NMS is in the works. SC would like to work with Geisinger. Could MP explore his database to see if dantrolene is used, for what reason, and its effect? MM will ask.

**Administrative Update:** DD shared the top focus of administration since April 2020. She asked SR to share the work she has done with the PAC. SR feels the PAC is not making enough recommendations. They have to make 2 groups: 1) work on consensus guidelines and publish papers and 2) look at the website's healthcare portions to update/clean up. DM shared the concurrent Education Committee's focus on healthcare professionals, patient/public and internal education. Their next committee meeting is scheduled for September 22. We are reminded the PACs responsibility is to verify all MH educational material. There is a possible overlap in focus areas and it was determined that the chairs of both committees will talk in order to clarify focus and eliminate overlap. HR feels the CME-accredited webinars will be an improvement. DM asked about connecting with others through the website and CK noted the PLC talked about how to connect and make "user generated content".

**Registry:** AG went over her report from the Registry as of July 24, 2020. She feels the conversions from data sent from Pittsburgh should be completed by February 2021. HR asked if, after that point, will elements be chosen and results given? Answer was yes. It was noted the NIH project could be shared via newsletters and social media. Looking for patients who were biopsy positive but genetic testing negative. JT noted he has about 200 biopsies from Tom Nelson's center he could send to the Registry.

**MH Hotline:** TP shared HLC/PAC meeting results. She shared her surveys to be sent to the doctors calling the MH Hotline and the HLC responding and asked for feedback. We are back to normal hotline call volume, post COVID. She hopes to publish the HLC/PAC Meeting summary, perhaps in APSF.

**Patient Liaison Committee:** CK noted when the next Scientific Conference is held, MHS patients would like to be part of the meeting and perhaps have some time to meet among themselves. Need to find a way for more interaction of MHS within MHAUS. He feels it is time to review the way the PLC answers MHS questions and perhaps share the duties more widely in the group. HR asked about the plans for the PLC and CK noted they are looking into a way to share more information to the person filling out a contact form and recording responses.

**Tom Nelson's Book:** After some discussion on the possibilities we know of so far and HRs comments on a fairly good amount so editing needed, this will be tabled for 1-2 months to allow JT to review the book and perhaps send to a few others for feedback as to whether to print or not. Sharon Dirksen and Tom Blanck might be options.

**Succession Planning:** JT verified with DD that her retirement date is April 30, 2021 and noted we need to set up an Interview Committee. JT asked DD to share what drew her to the position in the first place. JT and HR will be on the Interview Committee, but need another board member volunteer. Need to advertise the position. JT will take the job description DD provided to write up an ad. MP has contacts and could suggest someone who has experience fundraising and could help find someone to suggest. He will make introductions. JT noted GA will likely be retiring not that long after DD and we need to consider her succession planning as well. GA will need to give the board advance notice when she decides. This work must begin now and keep moving forward.

**Health Scholars Presentation:** Cole Sandau, CEO, shared what they are doing at Health Scholars with VR simulation. Started in 2018 with fires in OR. Their programs provide points for medical malpractice credit and thus can offer a reduction in insurance costs. Teach high quality skills, team skills and stress situational awareness. He worked very closely with Dr. Levine and the ASA. Now have 2<sup>nd</sup> generation voice-activated piece. They focus on high stakes/low frequency simulations that are very focused, e.g., high risk OR, resuscitation, peds. When showing the fire simulation, they are always asked about an MH scenario – some will pre-buy if it is built. They want to collaborate with us to get MH experts input. HS would cover development costs and look to us for clinical input and perhaps an endorsement? HR asked where their funding comes from. Reply was investors. The program is fully virtual and fully immersive experience to have total control. Step in and it works. They can control traps, escalation and response to test cognitive response of individuals. Full debriefing at the end with full explanation of what was done incorrectly. The program will not let the individual make a wrong choice and corrects errors and explains why as they are participating. MHAUS is the national standard of practice and they need our input. JS felt the potential seems to be huge. HS gives completion certificated for CE, but would need to work with accrediting agency for CMEs. Charges for their program was discussed and Cole advised he could send a video link to show the VR experience and could ship a VR kit to be shared within the board. DM asked how would we collaborate? Cole shared they need MH experts to review and share feedback and, when done, review the final program. They would share royalties with MHAUS on the sales. Initially, the MH VR simulation would be a stand-alone product, but later combined with others, like Fire Safety. Meeting for the day ended at 5:15 pm (ET).

## DAY 2 – August 9, 2020

*Board Attendees:* HRosenberg (HR), SCaroff (SC), BDenholm (BD), SNapolitano (SN). JTobin (JT), JCahn (JC), CKeller (CK), DMashman (DM), MMcMinn (MM), CMercer (CM), TPassig (TP), JSumanis (JS), SWatt (SW)

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Meeting began at 8:15 am with Investment update from **Leigh Baldwin**. Leigh noted our lowest point with the COVID effect was March 23<sup>rd</sup>. He relayed the Investment Committee met in March and decided to sell some stocks felt at risk and use the money to purchase others that also gave dividends. S&P is now up 4% for the year. JT noted DD and staff watch the expenses very closely to avoid taking funds from the investments, if possible. JT's Personal note: we held course in March, 1.5% of the population had COVID. We need to be prepared if no vaccine and huge increase in patients again later may affect our sales. We may need to take funds to remain solvent. SN agreed with this. HR asked about gold, silver and bitcoins. LB noted MHAUS has 70/30 split as a growth portfolio. He asked if the split should be adjusted to perhaps 60/40? At 0% interest, risk of bond portfolio is not helping. Negative interest rates mean dollars will flow to inflation and gold, etc. will improve. JT noted the retired committee members need to combat their normal practice of using some dollars from investments to supplement income and rather continue to

grow the portfolio for the organization. SN noted we have been stable and thoughtful, broadly diversified and in good shape, but must remain careful. HR relayed if anyone wants to join the committee, let any of the committee members know. LB noted Google stock is over 5% of the portfolio and we might want to consider selling some and purchasing something else. JT noted there could be a conflict of interest if we invest in Eagle and it might be seen as favoritism by other manufacturers. SN noted if working with Eagle we maybe gave support for their FDA submission; it could be seen as a conflict of interest. Genetic testing companies are probably not a conflict.

**CME-accredited Webinars:** JC asked for a breakout of who attends the webinars now. DD reported 87% are RNs, 10% are MDs and 3% patients/family. HR noted didactic presentations (webcasts) could be done periodically by experts in various areas like genetics/genetic testing, MH hotline cases, etc. JC suggested it be added as a free member benefit. Discussion followed about how to evaluate the didactic program to determine if a positive ROI is achieved and feedback is good. SC asked about sampling a small group of RNs to see if they are interested in CME/CEUs. **HR will talk to Education Committee to draw up a list of topics for didactic presentations/timing.** JT offered to share “canned lectures” he has already done and suggested others may have the same to share. He then asked about the difference between didactic presentations and webinars; HR replied presentation is same, content is different. Topic will require further work and investigation with updates for the board.

**Nonprofit Website Discussion:** All who reviewed websites reported on at least one of their choices. SW liked the idea of athletic blogs or toolkits from the Hemophilia website. She suggested the idea of a summer intern for help at the administrative office. They recognized donors at a specific level, for instance, visionary, trailblazer, etc. MM noted the Sudden Arrhythmia group showed mission on each page, lot of resources, clear MD referral network, more for providers. SC talked about Huntington’s site emphasizing getting family help. The Dystonia site made you scroll down a long home page, shared patient genetic research, they have a coalition supported by a grant and highlighted 1-day event with promo products to fundraise. JC asked why we were asked to review these sites? HR noted it was for feedback on what we might do with our own site. GA talked about the American Academy of Allergy, Asthma and Immunology and noted their membership is \$475/year. They have an “Ask the Expert” area and offer members free webinars. Support is large from industry.

JC talked about the MHAUS website and suggested changes need to be made. Cleaner and clearer – we have a lot of information all over and broken out as to 1) how to treat, blogs and 2) tools to implement. Two buckets: HCP and patients. JS noted as a user, still learning to maneuver, and does not find it intuitive; cluttered, might be worth an investment to redo. HR agrees there is a lot of information but not a lot of guidance to find what you are looking for. DD then shared how the website was revised into the present template format with side space for ads and topics often requested and the slider ad was added later for fundraising opportunities. TR asked about sending out a survey for feedback from our website visitors to obtain their thoughts?

**DECISION:** Discussion should begin within Executive Committee and administrative staff as to how to begin working on the website to improve it. Updates given to the board at monthly board – executive director calls.

HR summarized what he felt was determined as next steps from this meeting. Top Priority is Executive Director search. Other areas of focus are: 1) survey customers and funders for advice from others on setting up their websites and develop a concept for ours, 2) find additional advertisers for the website via board members suggesting contacts from their personal contacts, 3) didactic presentation topics/contacts like SW for exercise/sports, 4) results from “Ending MH” genetic studies, 5) *Health Scholars* presentation on VR simulations is of great interest and could help with Certification/Centers of Excellence goal, 6) complete hotline transcription/survey integration into RedCap, 7) MH fellowships (3 months to one year) for MDs and nurses, 8) review Tom Nelson’s book to decide if we publish or not (to Dr. Tobin for 2 months initially for his review/suggestion and other medical writers at the same time), 9) suggestions for research topics for the Registry.

Thank you to all who attended for their time and constructive feedback and ideas.

Meeting ended at 10:30 am (ET).

## August 8-9, 2020 Strategic Planning Meeting Action Items

Minutes from the April 24, 2020 Board Meeting approved.

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**DECISION:** Discussion should begin within Executive Committee and administrative staff as to how to begin working on the website to improve it. Updates given to the board at monthly board – executive director calls.

Scientific Conference will not be held in January 2021 due to COVID uncertainty.

HR talked about Twitch, the Amazon gaming site. Gaming topic was tabled.

It was noted we could consider becoming a *Center for Excellence*. Need to know more about the process. JS noted we could certify someone as an MH resource if we were a Center for Excellence. Admin staff will research further.

*The Communicator:* HR noted we could produce an online index of 10-20 recent issues.

TP noted we were going to put on an MH simulation at the 2021 ASPAN meeting, but tabled due to COVID. She will continue to work on this effort for a future meeting.

SC would like to work with Geisinger. Could MP explore his database to see if dantrolene is used, for what reason, and its effect? MM will ask.

There is a possible overlap in focus areas and it was determined that the chairs of both committees (Education and PAC) will talk in order to clarify focus and eliminate overlap.

MH Hotline: Teeda Pinyavat hopes to publish the 2019 HLC/PAC Meeting summary, perhaps in APSF.

Patient Liaison Committee: Need to find a way for more interaction of MHS within MHAUS.

Succession Plan: Top Priority is Executive Director search. JT verified with DD that her retirement date is April 30, 2021 and will take the job description DD provided to write up an ad. MP has contacts and could suggest someone who has experience fundraising and could help find someone to suggest.

Health Scholars: Cole Sandau advised he could send a video link to show the VR experience and could ship a VR kit to be shared within the board. DM asked how would we collaborate? Cole shared they need MH experts to review and share feedback and, when done, review the final program. They would share royalties with MHAUS on the sales. Moving forward with consideration of this collaboration.

CME-accredited Webinars: HR will talk to Education Committee to draw up a list of topics for didactic presentations/timing. JT offered to share “canned lectures” he has already done and suggested others may have the same to share.

Priorities: 1) survey customers and funders for advice from others on setting up their websites and develop a concept for ours, 2) find additional advertisers for the website via board members’ personal contacts, 3) didactic presentation topics/ contacts like SW for exercise/sports, 4) results from “Ending MH” genetic studies, 5) *Health Scholars* presentation on VR simulations for MH collaboration, 6) complete hotline transcription/survey integration into RedCap, 7) MH fellowships (3 months to one year) for MDs and nurses, 8) review Tom Nelson’s book (Dr. Tobin for 2 months initially to review/suggestion and other medical writers at the same time), 9) suggestions for research topics for the Registry.