

IOMSN Board Meeting

March 23, 2017

Convened at: 6:00 PM

Members Present: Megan Weigel, President (attended via conference call) Connie Easterling, Immediate Past President, Aliza Ben-Zacharia, President Elect, Patricia Pagnotta, Secretary, Beverly Layton, Treasurer, Rachael Stacom, Stephanie Agrella, Bonnie Blain, Cheryl Blaschuk, Del Thomas, Amy Perrin Ross, Marie Namey, Marie Moore, Mary Kay Fink, Lynn Stazzone, MaryAnn Hibbs, Meghan Kinnetz, Colleen Harris, Carol Chieffe, Lori Mayer, Jennifer Smrtka,

Staff Present: June Halper, Executive Director, Leny Almeda, Marguerite Herman, Lisa Skutnik, Roberta Elwell

Opening Remarks

Connie Easterling

1. Welcome--It's been a busy and good year.

Personal Update-Board Members

All

1. Colleen Harris- Preparing for vacation. Busy and well.
2. Bev Layton-- Very busy and University of Alabama now is a comprehensive center designated by NMSS. Also, hired a new LPN.
3. Carol Chieffe- Very active for Advocacy in Healthcare, her state will lose dollars, pre-existing conditions will never be accepted, works in PA, insurance advocacy for clients
4. Marie Namey- Indirect direct care has become insurmountable, PA, labs etc. burden of treatment, last month did week mission in Honduras- very humbled about what we have vs other countries
5. Meghan Kinnetz newest member to the board first year here largest MS Center in Iowa, she is the only certified nurse. She coordinated quarterly NP meetings and quarterly meeting for MS specialist in Greater Iowa to discuss journal articles.
6. Lori Mayer- Very busy with the development and launch of Live Wise MS, grandmother for first time this year, expanding research in her clinic to add Parkinson's studies
7. Bonnie Blain- smallest MS Center in Alberta but still growing, figuring how to work smarter. Has 4 sons 3 daughters and 7 grandchildren, Expressed appreciation to Marie Moore and all her efforts with the Membership committee
8. Marie Moore- Hails for Charlotte NC, transitioned from NP to inhouse infusion center Director, allows for her to be home 2 weeks per month, training and keeping standards up, doing some research, first poster at CMSC and maybe ECTRIMS
9. Racheal Stacom- NY Manhattan practice in the Bronx, MS and community based health care for disabled mostly Medicaid sponsored, working at looking at practice at how to help persons with heavy burden of disability and medications, learning motivational interviewing-learning via certified trainers

10. Aliza Ben-Zacharia- NY City NP challenged by all new medications and the indirect care. Has started teaching online research courses. Done with courses for PhD and using data from CombiRx to evaluate BMI and brain volume loss.
11. Jen Smrtka- NP U of Miami- mid-life examination, working with Dr. Rohammon, trying to be a realm of calm and the intuitive nursing, caring vs curing, optimize function and QOL- more symptom management and mindfulness vs focus on DMT, deep breathing and exercise
12. Stephanie Agrella Austin Texas with Lori Mayer- very busy year running, is focusing on symptoms. Is working and going to school. Active with local Advanced Practice. Hired a lobbyist to lobby for Advanced Practice, collaborating with Bryan Walker for CMSC for Advanced Practice, CME cruise for Advance Practice group
13. Tricia Pagnotta- Busy at work and at home on Farm with new fillies. Also, have granddaughter who will be two years old this week.
14. Del Thomas-from UK- On committee of Nurse Association and spoke in Parliament. Helped with Nurses at Ectrims, tried to push for council of sponsors for AGM, has sent up committees, MS Trust support nurses redefining nurse competencies for varied roles of nurses. Succession planning. Feel there are more nurses than we have on our registry would like to have the list of members. Nurses cannot get money to go to International Conferences. How can nurses get sponsorship? Answers -if you participate as faculty, can apply for scholarship up to April 15 th, lot of competition especially with RIMS We really do depend on pharma for our projects—pharma is not giving as much to IOMSN—Del won the Outstanding Nurse for Uk
15. Cheryl Blaschuk now working at medical college of Wisconsin
16. Mary Ann Hibbs- Pittsburg State College center just had a cat adopt her.
17. Connie Easterling- opened infusion center, all family is doing great but discussed the Pulse and both son and husband were on that night
18. June Halper- going to Lincoln Nebraska to see the eclipse on August 21st with Amy middle of country to VA, could see in Charleston.
19. Amy Perrin Ross- Partner in Eclipse crime, things that Jen spoke of hit home – no budget in the State of IL, therefore fighting for many things which never had to do before, forced to take a step back to be careful who to fight with, can't give up as if I don't fight who will
20. Megan Weigel- via phone baby is well and gained 1.5 pounds and he is growing, all going well, agree with others with comments about funding for programs and for patients. Joelle Masood form Lebanon
21. Lynn Stazzone became a grandmother 8.5 months old.

Review and approval of previous minutes of full board meeting 3/31/16

Patricia Pagnotta

Motion to approved by Amy Perrin Ross and then seconded by Beverly Layton

Executive Report

June Halper

Motion to accept by Tricia Pagnotta and then seconded by Meghan Kinnetz.

Board Discussion

Mentorship

Rachael Stacom

Discussed the \$75,000 of grants. Nurses who are dedicated 7 are going to Stoneybrook in May to begin their mentorship, many are from rural areas. June did submit grants to all pharma companies. Please talk it up so this continues and hopefully we will get funding. Do photo shots while they are there so we can post these on our site and at CMSC

Dinner/Awards

Beverly Layton

Dinner and awards evaluate votes for awards winners for 2016 are: **June Halper Award: Thumbs Up Award: Research Award, Linda Morgnate Hope Award:**

Connie discussed the awards. Leny has had 27 responders but don't have enough for all the awards. Deadline is April 7th. Committee was listed. 3 board members are rotating off.

We do keep this confidential Jerry Wolinski is getting a lifetime award on Friday

Dinner- discussion of meeting Bev, and MaryKay several conference calls. All board member will be asked to greet persons. Keep agenda brief so we have plenty of time for celebration, want to acknowledge all the past and our history. We will have a live band for celebration from 9-11 pm all the other dinners will be invited to come to share. List of songs are being passed around. We will have a cash bar for those who want to drink. IOMSN booth signup sheet is going around. Set up for the dinner- the liaisons are going to do this and not more will be needed. Board should show up by 7pm.

We need to expand on our stamp of approval for IOMSN and we need to market and charge for this

Do we need to send out email about booth coverage? Roberta will be at the booth.

Nominating Committee

Connie Easterling

Connie will be organizing the Nominations and will gather board members to participate in selection process once she is sure all meet the criteria. Patricia Pagnotta, Beverly Layton, Meghan Kinnetz, and Marie Namey agreed to participate in process.

VA Reports

Maryann Hibbs

VA has a National MS compository of all patients and letters are sent out to patients.

We do have some criteria for use for DMT, home to home computer system are being used for in home conferences. Heidi Malone has done a 2-part nursing instruction, IOMSN hyperlink is on their website. Please give us the site go on the VA website and look for MS and we can find the centers listed.

International Report

Del Thomas

Presented what the UK nurses are doing. All nurses are members of UK and with the joint work with MS Trust hoping this will help with building relationships. Can others submit abstracts for ECTRIMS? Del is not aware.

Open Discussion

Megan Weigel wanted to thank all committee chairs and members for the hard work which has been done.

Marie Moore asked if an Austrian nurse be on the speakers' bureau. Colleen stated--we will look at this, we could do this if there is a need, they need to be IOMSN member and certified. We also like to have some information about the quality of the speakers. If they use our educational materials we would like feedback like sign in sheets and evaluations. Colleen reminded up the IOMSN does have Spanish slides. Speakers do have access to the training tools. Probably could use the same application just need to make sure location is mentioned. Precedence has been set as we have an international speaker now.

There will be 72 exhibitors at the annual meeting.

Meghan Kinnetz had a logistics question regarding the annual IOMSN board meeting. "Can this be done in one day event?" June replied this meeting cost IOMSN money should be done in conjunction with the sponsor of councils meeting. There was general discussion about the Council of Sponsors meeting. In general, the consensus was the Council of Sponsors needs to more interactive and IOMSN being more assertive regarding our needs. Marie Namey, Aliza Ben-Zacharia, and Amy Perrin Ross felt we need to continue the Council of Sponsor meeting. Discussion regarding timing of meeting. Maybe we could start our board meeting earlier in the day and then break for Council meeting then finish after Council meeting. Marie Moore thought this format may allow us to have a more robust way of making this presentation. Racheal Stacom questioned if we should send survey to the attendees and those invited to the Council of Sponsors meeting as to thoughts or desires they have in partnering with the IOMSN. It would be good if each company could speak and allow them to spend a few minutes talking about their company's ventures, Megan Weigel thinks this continues to be a worthy event we could scale back on the way it is done. This year unfortunately the persons in the companies who make the decisions were not there except for Mallinckrodt. We need to be better marketers to be more effective. Some work does happen before and after. We probably should spread out so that we were at all tables. We need to be more direct we were too subtle. Give them more information about what is being offered in these programs—details of programs. Like the idea of us meeting first then going to Council. Start at noon-2pm social 2-3 and council 3-5 then finish that night. We should start with committee reports have one committee member share info and another to share the budget request. They need to see the value of what we do.

We need to do research as to the value we provide for these companies. Maybe we should use the Coalition to ask questions about what the impact nurses have on MS patients. This will spread out to other specialties. CMSC is offering \$40,000 for a pilot project. Lori will get the committee to submit a proposal to CMSC. Aliza- Can we do a monograph about what IOMSN does? We do so much which does not bring in money. How many RNs bill for what they do? We have not taught ourselves to bill. Ambulatory nurses are trying to bill for telehealth. Nurses care and we are nice but we are not

IOMSN Schedule of Cash and Cash Equivalents for Year Ended 12/31/16

Beverly Layton

Budget- discussed draft of financial statements will have a surplus but is not as good as in the past as due to not as much pharma support Biogen has turned us down for 2 grants. We need to be more conscious about money expenses and need to use regional speakers. Pg. 9 is the bottom line being turned down for MS counselling points We need to come up with funding. Can we donate to our funds? We have 1.9 million as we paid MS Live bill, we need to be smarter and protect our survival. This may be a swing. We all need to push our relationships with pharma we need to try and to use this. We may need to organize Ad Boards for pharma companies. Jen Smrtka pointed out we are losing money to other competitor organizations- giving a lot of money to patient run educational programs. Aliza Ben-Zacharia commented on the success of the program for Lemtrada. Can we expand this to Genentech and can we also train their nurses? Megan Weigel, Marie Namey and Meghan Kinnetz will review a draft to approach to pharma about meeting planning. Think about what are you offering be mindful of who is charge. Need to have patients as one of our motivators.

Motion to approve budget Carol Chieffe and then seconded by Tricia Pagnotta. Approved.

Membership Report

Marie Moore/ Bonnie Blain

Membership is static and environmental changes. We are going to have a reception at CMSC, cash bar for getting together on Thursday from meeting prior to dinners. Trying to update the speakers' bureau. Please come to our reception/happy hour. Needs letters to acknowledge the scholarships and Stoneybrook (June Halper got additional 10 scholars due to pharma) this is IOMSN sponsorship. We have 80,000 for dinner this year.

Research Committee

Lori Mayer

Committee members were given. Reorganize as to how to distribute grants and what is available and what are the items they can apply for, this is to allow for more to be able to apply, also make it easier for persons to apply. Many good mentors on committee wanted to provide support for persons and training, assist in editing, Emphasis on the fact that all committee members are good resources, each quarter 15 min pod cast and do interview. Del has a research module that she would be happy to share. Also need information just for EBP not totally research. Jen Smrtka commented we need to market ourselves as the only global organization and we could do global research. Meghan Kinnetz Peer program for research, Lori-this is there but we need to make persons aware of this, Maria Moore emphasized discussion can you come during our happy hour at CMSC. Colleen Harris noted we haven't been able to draw persons to research workshops at CMSC. Aliza Ben-Zacharia commented need smaller local venues. Marie Namey commented we talked last year about doing a one day conference and charge a little for this, June Halper stated we could develop a program to send to institutions. Lori will look at these suggestions in the Committee.

Future plans- love to do mentoring pod casts which could be available on website. List of suggested journals persons can apply to write articles for. Working on trying to collaborate with interested nurses to encourage more research. Question from June Halper can we develop a listing of nursing who have done research or are doing research, put on website. Lori Mayer committed to make this an action plan.

In addition, will pose the question of a Webinar for persons or a live program. Lori will make a flyer for the booth at CMSC

Education Committee

Colleen Harris

Sponsored Educational Events 2016-2017 were reviewed. See report dollars are down we are hoping to get more programs for this year. Trying to build the speakers bureau to have local speakers. She gave a shout out for case study presentations to put in data bank.

She was requesting two volunteers one for DMT and one for the Understanding of MS evolution.

Clinician reviews we have had 4 persons write so far. Anyone who wants to contribute please let Colleen know this is a column based for interest to primary care NPs.

At CMSC we are doing a course on MS Nursing. The foundations of MS Nursing will be international, 2 Canadians and 2 USA nurses and Australia.

Need innovative ideas for nursing content at CMSC. Trying to bring in new nurses. How we deliver regional programs. DMT teaching should be done but we need to focus title on aspects so we are not known for DMT like challenges of aspects for dmt, nursing concepts around DMTs, focus on treatment so you can focus on DMT and symptoms

Kathy Bolen is leaving to teach.

Fellowship/Scholarship

Marie Namey

Committee reviewed 10 applications for scholarship for awards ranging from \$750 (to support MSCN exam) to \$1000 for a total of \$10,000. Persons could not have two years in a row.

Additional reviewed 10 scholarships for CMSC certification through June Halper donated by Serano \$18,000. Grant covered meeting, study materials, and certification test.

Possible next year sending out a google email to announce scholarships, and await all applications for all can be scored and thus having a more competitive process, continue to advertise with regional liaisons. By March first need to have applications. Marie wanted to acknowledge Amy Perrin Ross stating she should get Hero Award to her reviewing abstracts as this year there was a glitch and all reviews were not saved to Amy had to hand recreate all work done and her co-chair was unable to help.

Bylaws

Amy Perrin Ross

Report as stands. We are in good shape. Cheryl Blaschuk is willing to help with the bylaws.

Communications Web Committee

Rachael Stacom

Report is as stands, biggest new is the new website thanks to leny big clean up and removed older items and those who did not have references.

Future: How can the web site support all the committees. Pod cast are exciting.

financially savvy. WE NEED TO DO THIS RESEARCH THIS SO WE DON'T PUT OURSELVES OUT OF BUSINESS.

Lisa Skutnik suggested the IOMSN do an annual report which demonstrates who does what (what company for what) Do this before the meetings. Megan Weigel media blast as to our value, Jen Smrtka suggest we start small then expand once we have the revenue, just do what we have with redoing the marketing materials. Aliza annual report with the monograph of what we do. From Megan Weigel are we putting this into an action? From Amy Perrin Ross, this is an operations issue which June and staff can do.

We did get word Biogen is continuing our Counselling Points.

Amy Perrin Ross questioned Heidi Malone is the IOMSN board meeting to the MSCINB. If she is a member of the MSCINB she cannot be a liaison to the IOMSN board. We need to clarify this to the persons. Megan will need to name another Liaison to the MSCINB.

Megan and Connie thanked all board members.

Marie Namey motion to adjourn and Lori Mayer seconded.



IOMSN Executive Director's Report **2016-2017**

Administrative Activities/New Programs

The IOMSN administrative office functions very smoothly with a collaborative and motivated team. Leny Almeda and Roberta Elwell, backed up by Marguerite Herman, provide us with their expertise to see that operations runs smoothly. Peter Porco and Kelly Walters, handle our financial records and provide us with their expertise and oversight. William Katchen, CPA, reviews our financial records on a regular basis. Leny Almeda is responsible for maintaining membership records, assisting with the educational programs, and other activities that occur throughout the year. Leny keeps the website current and works with the Communications Committee to post their activities as requested. She has updated the website and monitors the Google Group which is very active and communicative. She coordinated the mentorship recruitment which generated 35 applicants (choosing 7 instead of 6) and she will work with Stony Brook and British team to coordinate the logistics assisted by Marguerite Herman who will work on the hotel and travel. Leny also works with MSNICB to maintain their website. Assisted by Marguerite, MSCN certificates and certification update material are overseen by Leny.

Membership

Marie Moore will be providing us with a comprehensive report on membership but from the administrative perspective, we continue to grow and inspire other nurses globally to join our ranks. The regional liaisons (representatives) are excellent resources for outreach.

Educational Activities

The CMSC annual meeting continues to be our largest program with more nursing sessions being offered each year along with a fundamentals course that prepared nursing and non-nursing healthcare professionals for their respective certification examinations. We have had numerous educational programs throughout 2016 including live programs regionally; online live programs via webinar; printed enduring activities; and collaborative programs with the CMSC and its educational partners. We are working with Tom Garry and his colleague, Susan Panetta, who are developing

IOMSNNews, a quarterly online publication funded by a grant from Genentech. Colleen Harris has approved this project that will be edited by Marie Moore.

As stated above, our mentorship program (**Mini Nurse Fellowship**) will take place under the auspices of SUNY at Stony Brook on May 15-May 18th. Seven nursing professionals will participate (one from Canada) in a diverse and information packed program thanks to Pat Melville and her team in the US and UK.

Publications

The IJMSC continues to be well-received and widely circulated. There are many special issues along with the publication which is now released six times a year. There are many articles of great interest to nursing professionals. There have been three CE articles in the journal beginning in 2016 with a current article in February (Framework of MS Care Part II).

Website

The website and our list serve continue to grow and serve as an excellent resource for MS nursing professionals. Coordinated by Leny Almeda and overseen by the Communications Committee, it is a lively and current site for MS nurses globally. Its recent update brings us into the 21st century. It is a wonderful and rich resource and is being monitored and constantly updated to keep it current.

Committees

Our committees continue to function effectively. I work closely with all committees assisted by Leny, Roberta, and Marguerite with assistance from our financial team.

Council of Sponsors

The Council meeting offers us a rich opportunity to interact with industry and provide them updates about our activities.

Research

We have posted a course on research on our website. There are new rules posted by Lori Mayer and her committee. There have been no applicants as of February 22, 2017.

Certification

The MSNICB, under the leadership of Mary Kay Fink and her active colleagues. Therese Burke has completed her term and will be moving to Asia with her husband for the next

two years. The MSNICB meeting will take place concurrently with the IOMSN board meeting in March. . They will be joined by a Portuguese nursing colleague to enhance the examination for international colleagues. The exam is now offered in Portuguese, Dutch, Spanish, and French.

LiveWiseMS

The IOMSN received a grant from EMD Serono to establish a new educational website entitled LiveWiseMS (www.livewiseMS.org) We have a partnership with Wolters Kluwer and the site contains peer reviewed references and commentaries, videos, resources, rich links and other important information for patients, families, and the professional community. Lori Mayer is the chair and her committee consists of Megan Weigel, Colleen Harris, Marijean Buhse, and Cathy Chester (a woman with MS). LiveWiseMS has a strong social media presence. Cathy has blogged frequently with updated information about the site.

Miscellaneous

I am honored to function as your Executive Director/CEO and appreciate your help and support throughout the year. Please feel free to provide your input and suggestions to improve our administrative functions and continue to serve our membership in the best possible manner.

Submitted by: June Halper, MSN, APN-C, MSCN, FAAN
February 22, 2017