

IOMMSN News

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A Publication For – and By – IOMSN Members

Encouraging Fitness in MS



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REGISTER NOW FOR MS 2017: THE SPECTRUM OF MS NURSING

It's back-to-school time, and in step with the season, the International Organization of Multiple Sclerosis Nurses' (IOMSN) is offering its members and other nursing professionals a one-day continuing education activity that will cover a wide range of issues related to MS care.

MS 2017: The Spectrum of MS Nursing offers registered nurses and nurse practitioners 7.5 contact hours of continuing nurse education, with 3.0 of those credits in the area of pharmacology. The Educational Design Activity is jointly provided by the IOMSN and Nurse Practitioner Alternatives (NPA), which is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's (ANCC) Commission on Accreditation. (Accreditation does not imply endorsement by IOMSN, NPA, or ANCC of recommendations or any commercial products displayed or discussed in conjunction with the educational activity.)

The activity entails a one-day live meeting, running from 7:45 AM to 4:45 PM, with sessions being held:

- Sept. 9, Billings, MT
- Sept. 16, Wilmington, DE
- Sept. 23, Albuquerque, NM
- Sept. 30, St. Louis, MO
- Oct. 7, Jersey City, NJ
- Oct. 14, Overland Park, KS
- Oct. 21, Jacksonville, FL

Topics to be covered include "What We Know About MS in 2017: A Comprehensive Review," "Therapeutic Options and Targeted Therapies," "Setting Priorities in MS Nursing Care – Complex Case Strategies," "Symptomatic Management of MS and the Role of the Team," and "Case Studies and Symptomatic Management – The Role of Nursing."

Pre-registration is required, as there will not be on-site registration. While registration is free, registrants will be asked to provide credit card information to guarantee their spot. The credit card will be charged a one-time \$25 fee only if a registrant does not attend and does not cancel her or his registration at least 96 hours or 4 days in advance of the session.

To register for the activity, and to obtain additional information on the curriculum, the companies supporting the program with grants, and related information, please visit <http://iomsn.org/ms-2017-the-spectrum-of-ms-nursing/>.

Not able to attend one of these live events? Then take advantage of the wealth of other educational opportunities the IOMSN offers on its website. A full list of educational activities, many of which provide continuing nursing education contact hours, and other resources can be found at the Tools & Resources section of the IOMSN website, <http://iomsn.org/>. 



Letter FROM THE Editor

LOOKING BACK ON A MAJOR MILESTONE – AND AHEAD TO EVEN GREATER THINGS

I hope you've had a wonderful summer and are poised for a great fall. That certainly is the case for the International Organization of Multiple Sclerosis Nurses (IOMSN).

We launched into summer by celebrating the organization's 20th anniversary at a festive gala in New Orleans just before Memorial Day. Held in conjunction with the Consortium of Multiple Sclerosis Centers' (CMSC) Annual Meeting, the IOMSN bash featured everything from the joyous music and delicious food of the Big Easy to the much-deserved recognition of several IOMSN members and others who have made outstanding contributions to MS nursing and patient advocacy. This issue features coverage of that event, as well as a profile of Kelsey Lenihan, RN, NP, MSCN, who received the June Halper Award for Excellence in MS Nursing at the celebration.

Looking ahead, meanwhile, the facing page offers information on MS 2017: The Spectrum of MS Nursing, an excellent, one-day continuing education activity being offered at seven locations across the U.S. from Sept. 9 to Oct. 21. Whether you attend one of those live programs or avail yourself of the IOMSN's extensive online educational offerings, our Organization provides numerous opportunities for you to enhance your skills and accomplish even greater things as an MS nursing professional.

Other articles in this issue address two topics that are always in season:

- Lori L. Mayer, DNP, MSN, RN, MSCN outlines an innovative program she started to encourage her patients to be physically active. She shares practical strategies for motivating patients to start – and continue – exercise regimens appropriate to their overall health status.
- Meghan Kinnetz, MSN, FNP, MSCN, discusses the insights she has derived from talking with dozens and dozens of fellow MS nurses in her role as Midwest Regional Liaison for the IOMSN Membership Committee. She also details how she and her fellow Regional Liaisons serve as a resource for current and potential members.

Our Regional Liaisons are there to listen to your ideas and concerns, and so am I in my role as editor of *IOMSNNews*. This is *your* publication, and I'm eager to know what topics you would like to see addressed in future issues. So please email me at editor.iomsnews@amicohealth.com or write me in care of our publisher, Amico Healthcare Communications, at P.O. Box 501, Glen Rock, NJ 07452-0501.

I look forward to learning your thoughts. Meanwhile, best wishes for the new season just ahead.

Sincerely,

Marie



Marie Moore,
MSN, FNP-C, MSCN
Editor, *IOMSNNews*



MEMBER PROFILE

Kelsey Lenihan, RN, NP, MSCN

JUNE HALPER AWARD RECIPIENT GOES BEYOND THE CLINIC TO ADDRESS PATIENT NEEDS



Kelsey Lenihan, RN, NP, MSCN, relaxing at the beach with her daughter, Eile.

Kelsey Lenihan, RN, NP, MSCN, gives new meaning to the term “comprehensive care.” As a nurse practitioner at Hope Neurology in Knoxville, TN, Ms. Lenihan provides medication and symptom management, health and mobility assessments, wellness education, care coordination, counseling regarding clinical trials, and all of the other services entailed in meeting the medical needs of people with multiple sclerosis (MS).

But her definition of comprehensive care extends well beyond those tasks. It encompasses buying and delivering workout clothes and sneakers (along with a note reading, “No excuses. Go take care of YOU”) to a patient who had kept deferring exercise, citing the time demands of caring for her family and a lack of athletic apparel that she would feel comfortable and confident wearing to the gym. It includes reserving the seat at the head of her family’s dinner table on Thanksgiving Day for a patient whose husband of 40 years had died of cancer earlier that year. And, on other occasions, it has meant delivering groceries to a patient’s home, helping an overwhelmed patient clean her home, and – when the scope of her own skills had been maxed out – delegating to her ‘significant other’ a handy man to-do list compiled by a recently widowed patient desperate to repair and then sell her home.

In recognition of both her outstanding clinical work and those “above-and-beyond” efforts, the International Organization of Multiple Sclerosis Nurses (IOMSN) honored Ms. Lenihan with the 2017 June Halper Award for Excellence in MS

Nursing. Named after June Halper, MSN, APN-C, FAAN, MSCN, the founding Director and current Chief Executive Officer of the IOMSN, the award “represents leadership and creativity in the care of people with MS and their families,” the IOMSN notes. The organization adds, “The award signifies an energy of purpose to provide the most up-to-date comprehensive care possible.” Ms. Halper and Constance Easterling, MSN, ARNP, CRRN, MSCN, Immediate Past President of the IOMSN, presented the award to Ms. Lenihan in New Orleans in May, when the IOMSN held its 20th anniversary celebration in conjunction with the Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC).

To Ms. Lenihan, the broad scope of patient assistance she provides merely reflects the reality that the needs of people with MS go well beyond the purely medical. “At the end of the day, it may not be about the medication, the steroids, or the physical therapy. I want to know the one thing that is keeping a patient from moving toward a trend of more good days than bad. If it’s a lack of work-out clothes, for example, we’ll get that sorted out.”

The nurse practitioner attributes that mix of compassion and “can-do” thinking to three sources: her experiences as an athlete, her family, and the culture that neurologists Sibyl Wray, MD, and David Brandes, MD, have created at Hope Neurology, one of the largest MS clinics in eastern Tennessee.

Ms. Lenihan notes that playing soccer in high school and college instilled a deep appreciation

for the value of teamwork and persistence – but she also acknowledges that her former teammates on the University of North Carolina-Asheville women’s soccer team initially scoffed at her career choice. “They knew me as ‘Ol’ Yeller,’ because the only time I had to sit the bench in my college career was after a concussion and after getting too many yellow cards in one season. They strained to find the compassionate side of me that would be suited to nursing.” She continues that her family provided her with both the toughness and the emotional openness essential to her work. “While I grew up in a ‘walk it off’ household, and carry some of that with me in my nursing care, I also come from an ‘I love you’ family. It is not unheard of for me to hug my patient after our visit, tell them I love them, and tell them to tell their family, ‘Hi,’” she explains.

Meanwhile, she adds, Drs. Wray and Brandes have fostered an environment at Hope Neurology where all staff members are focused on identifying and addressing the full range of needs of people with MS. Ms. Lenihan explains, “Besides their typical ‘job responsibilities,’ my coworkers also go above and beyond. The last three years, we have had a team that does the National MS Society Challenge Walk in Savannah, Georgia. We walk 50 miles over three days, and our team name, fitting in more ways than one, is “Team HOPE (We Finish)”. We raise money as a team, and pound out 50 miles as a team. And just two weeks ago, our lab tech took it upon herself to paint encouraging and inspiring quotes on river rocks and scatter them around the office and in the infusion suite. The patients are absolutely loving them!”

Ms. Lenihan admits to some trepidation when the opportunity to join Hope Neurology arose. After graduating from UNC-Asheville with a degree in psychology, she spent a brief, unfulfilling time working in public relations before enrolling in a community college nursing program and then going on to obtain her bachelor’s degree in nursing from Eastern Tennessee State University and her master’s in nursing at the University of Tennessee (delivering her now 7-year-old daugh-

ter just as she started graduate school). She had worked in neurology throughout her nursing career, starting on the neuro/stroke floor at UT Medical Center and later working in epilepsy.

“I was apprehensive about a chronic disease. I was used to stabilizing folks and then sending them home,” she says. Also, Ms. Lenihan acknowledges, the prospect of working with Dr. Wray was somewhat daunting because the neurologist had a reputation for very high standards and fierce patient advocacy. “I asked a friend of mine who happened to be in pharmaceutical sales, and he said, ‘Sibyl Wray. You *cannot* not take this job. She is simply amazing.’ And she is.”

Ms. Lenihan adds, “I remember three things very clearly from my interview with Dr. Wray. The first is that when I said, ‘Yes, ma’am’ to a question, she pseudo-sternly advised me to not call her “ma’am” again. The second is that she told me that she wanted me to know our patients. She wanted me to know their primary caregiver, their occupation, the occupation they loved when they had to stop working, their children and grandchildren, and how many times they get up in the middle of the night to go to the bathroom. The third is that she was adamant that my family not be put on the back burner in order for me to work for her. I said, ‘I will absolutely do two of those three things, but with all due respect, as intimidating as you are, the threat of my mother knowing I didn’t call you ma’am is far scarier.’”

Today, nearly 5 years after she joined Hope Neurology, Ms. Lenihan adds, “Dr. Wray is a brilliant, generous, and funny friend in and out of the office. We generally alternate on patient visits, and we constantly collaborate on patient care – well, she really only needs me to reach things in high places, but I go to her often. I am also lucky enough to see Dr. Brandes a few days a week,

“I want to know the one thing that is keeping a patient from moving toward a trend of more good days than bad.”

— KELSEY LENIHAN,
RN, NP, MSCN

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ENCOURAGING FITNESS IN MS: AN EXERCISE IN EDUCATION

Connecting people with multiple sclerosis (MS) with fitness programs tailored to their needs is an exercise in education, says Lori L. Mayer, DNP, MSN, RN, MSCN.

“Patients need to understand that they can be healthy in spite of their MS, and that there is growing evidence that exercise provides numerous benefits for people with multiple sclerosis. Meanwhile, fitness professionals need to understand the relapsing-remitting nature of most cases of MS, and the implications this has for training regimens,” she says.

Dr. Mayer speaks from her experience in launching a fitness program for the patients of Central Texas Neurology Consultants/Multiple Sclerosis Clinic of Central Texas in Round Rock, TX, where she serves as Director of Medical Research Services.

An avid exerciser, Dr. Mayer wanted her patients to enjoy the same benefits she long has

derived from working out, and so approached a local fitness center about a pilot initiative. The center’s management was receptive to the idea, and the local chapter of the National Multiple Sclerosis Society (NMSS) provided financial support so that patients could participate in a 6-month program for a modest fee.

“Each patient had a baseline assessment with a physical therapist. The therapist, the fitness center trainer, and I then discussed the findings of that assessment so that the trainer could implement an individualized plan, focusing on specific muscle groups, goals, and activities,” Dr. Mayer explains. She adds that it was important to provide the trainer with an overview of MS, its pathophysiology, manifestations, and disease course.

“Trainers are used to seeing people make steady progress as the weeks go by. They need to understand that in MS, the frequency and intensity of symptoms can change, and that there likely will not be that sort of linear trajectory. They also needed to know about relapses, and that in the aftermath of a relapse, patients have to work over time to regain the progress that had been made previously, and in some cases won’t get all the way back to where they had been, but that they still are deriving benefits from the work the trainers are doing with them,” says Dr. Mayer.

Patients need a similar appreciation of the fact that they may experience both gains and some setbacks in terms of their exercise capabilities, but that participating in a fitness program is far preferable to a sedentary lifestyle, she notes.

“Typically, MS patients are less physically active than the general population, and this can detract from their overall health in terms of everything from excess weight to psychological outlook. It is important to share with them the highlights of scientific studies showing that exercise is associated with numerous health and quality-of-life benefits for people with MS,” adds Dr. Mayer, who serves as chair of the Research

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Check Out [msptathome.com](https://www.msptathome.com)

Realizing that many people with multiple sclerosis (MS) aren’t able to get to the gym regularly because of time pressures, transportation issues, or other challenges, Lori L. Mayer, DNP, MSN, RN, MSCN, collaborated with a physical therapist and personal trainers to develop an online training and endurance program suitable both for patients who are ambulatory and those who use wheelchairs. The site is available at <https://www.msptathome.com/>



Exercise (Continued from page 6)

Committee for the International Organization of MS Nurses (IOMSN).

The 6-month program that Dr. Mayer piloted with the fitness center included both aerobic and resistance training. Most of the program's 20 participants chose to continue with their fitness regimens after completing the initial 6-month course. On the strength of that experience, Dr. Mayer is exploring a number of options for encouraging more people with MS to include regular exercise in their lives.

"We're working on a program specifically for people in wheelchairs, and also are looking at an online program," notes Dr. Mayer, whose

MS advocacy work also includes service on the editorial board of the *International Journal of MS Care* and as Chair of the editorial board of LiveWiseMS.

"As is the case with all of us, if people with MS are going to exercise on a regular basis, they have to find the experience enjoyable, and they have to understand the benefits it offers. For people with MS, one of the most important benefits of exercise may be the opportunity to be pro-active in the face of a serious chronic condition, and to enjoy that sense of self-efficacy that comes from committing to making a positive change in your life," Dr. Mayer notes. 🌍

The Benefits of Exercise in MS: A Sampling of the Recent Literature

The last year alone has seen significant growth in the scientific literature documenting the health benefits of exercise for people with multiple sclerosis (MS). Three recent studies yielded the following findings:

- **Aerobic exercise and improved memory.** A blinded randomized controlled trial assigned 80 women with MS to an exercise group – whose members participated in 12 weeks of supervised, progressive treadmill walking -- or a control group. Before and after the 12-week period, all participants were administered the California Verbal Learning Test-II (CVLT-II), which measures learning and memory, and underwent magnetic resonance elastography (MRE) scans for measurement of shear stiffness and damping ratio of the hippocampus. Intervention group members showed small-to-moderate positive effects on CVLT-II performance relative to the control group, and those CLVT-II results were strongly associated with change in hippocampal characteristics measured on MRE.¹
- **Water-based exercise enhances physical conditioning in people with MS.** In a study of 26 people with MS, researchers assigned 13 par-

ticipants to a control group and 13 subjects to an exercise group whose members performed 45-60 minutes of aquatic exercise three times a week for 12 weeks. At the end of the study period, the people in the exercise group performed better, on average, than those in the control group on measures including the timed 7.62 meter walk test, the Getting up from a Sitting Position Test, and a balance test.²

- **Physical activity improves sleep in people with MS.** A study of 60 patients with MS examined whether there was a correlation between patients' level of physical activity and their wake after sleep onset (WASO) and other sleep characteristics. The researchers found that increased degrees of physical activity correlated positively with more favorable sleep characteristics.³

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MEET YOUR MIDWEST REGIONAL LIAISON: MEGHAN KINNETZ, MSN, FNP, MSCN

Meghan Kinnetz, MSN, FNP, MSCN, hears one question over and over again in talking with fellow multiple sclerosis (MS) nursing professionals throughout the Midwest: How can I get my patients the resources they need?

Helping her colleagues answer that question is just one component of Ms. Kinnetz's work as a regional liaison for the International Organization of Multiple Sclerosis Nurses' (IOMSN) Membership Committee.

"The role of a regional liaison entails staying in close touch with IOMSN members in a given geographical area, and being aware of the trends affecting them and their patients," says Ms. Kinnetz, a board-certified nurse practitioner at the Mercy Ruan Neurology Clinic and Research Center in Des Moines, IA. Additionally, "Regional liaisons work to identify educational needs, foster collaboration, and point colleagues toward tools, programs, and information that will enhance their professional development and well-being,

and help them help their patients."

IOMSN Membership Committee Co-Chair Marie Moore, MSN, FNP-C, MSCN, explains that the regional liaison system was instituted to further strengthen



Meghan Kinnetz, MSN, FNP, MSCN, with her family.

ties and communications between the organization and its members. "We have 5 regional liaisons throughout the US and 3 covering Canada," explains Ms. Moore, who worked with her fellow Membership Committee Co-Chair, Bonnie Blain, RN, MSCN, of Red Deer, Alberta, Canada, to implement the system. (See "How to Contact Your Regional Liaison" below.)

In an era of high patient volumes, constrained reimbursement, and increasing demands from government agencies and private payers, being active in the IOMSN is more important than ever, Ms. Kinnetz says. "It's really important that nurses recognize that the IOMSN is there to support them and their nursing practice. In particular, nurses really can and should utilize everything available to them from the Organization's website (www.iomsn.org) at the click of a button."

Ms. Kinnetz explains that she started her nursing career in a neonatal intensive care unit (NICU) and then moved to a pediatric emergency department and adult critical care unit (CCU) before having an opportunity to work with Bruce Hughes, MD, Director of the Ruan Multiple Sclerosis Center of the Mercy Ruan Neurology Clinic and Research Center. "I absolutely fell in love with MS under his leadership," says Ms. Kinnetz. "I became an IOMSN member shortly after making that move almost 5 years ago, and I have found the resources and mentorship opportunities that the organization offered to be a tremendous help," she says in urging other nursing professionals both to explore a career in MS and to become involved with the IOMSN. 🌐

How to Contact Your Regional Liaison

Have a tough question, good idea, or vexing challenge that you really want to run by other MS nursing professionals in your area? If so, getting in touch with your IOMSN Membership Committee regional liaison is a great first step. Those liaisons are:

- **Northeast:** Joan Ohayon, MSN, BSN, CRNP, MSCN – iomsn_northeast_usa@mscare.org
- **Southeast:** Patricia Pagnotta, MSN, BSN, CRNP, MSCN – iomsn_southeast_usa@mscare.org
- **Midwest:** Meghan Kinnetz, MSN, FNP, MSCN – iomsn_midwest_usa@mscare.org
- **Southwest:** Martha Mann, RN, ADN, MSCN, CRND – iomsn_southwest_usa@mscare.org
- **West:** Jong-Mi Lee, MSN, FNP, MSCN – iomsn_west_usa@mscare.org

THE IOMSN MARKS 20 YEARS WITH A BIG BASH IN THE BIG EASY



There's no better place to let the good times roll than New Orleans, and that's exactly what hundreds of International Organization of Multiple Sclerosis Nurses (IOMSN) members and supporters did on the evening of May 24, when they gathered at the city's Ernest N. Morial Convention Center to mark the 20th anniversary of their organization's founding.

IOMSN members donned Mardi Gras masks to enjoy a celebratory dinner featuring Cajun and Creole specialties, then danced the night away to the music of a Zydeco band. The dinner was held in conjunction with the 31st Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC), which took place at the



Featuring the "eyewear" for which New Orleans is famous, IOMSN Immediate Past-President Constance Easterling, MSN, ARNP, CRRN, MSCN, announces award winners. (Photo credit: The Photo Group)

and many achievements of the Organization.

Ms. Halper and Constance Easterling, MSN, ARNP, CRRN, MSCN, Immediate Past-President of the IOMSN, honored several of their colleagues for outstanding contributions. They presented the June Halper Award for Excellence in MS Nursing to Kelsey Lenihan, RN, NP, MSCN, of Hope Neurology in Knoxville, TN (See page 4 for a profile of Ms. Lenihan and her work.)

Hala Darwish, PhD, MSN, BSN, of the American University of Beirut in Lebanon, was this year's recipient of the IOMSN's Research Award. The organization's first LiveWiseMS Award, which recognizes the contributions of an MS nurse

in sustaining health and wellness in herself, her patients and their families, and her colleagues, was given to Moira Baynes, RN, BSN, MSCN, of

the convention center from May 24 to May 27.

The gathering also was an occasion to reflect on the accomplishments of the IOMSN and to recognize the work of a number of its members. IOMSN President Megan Weigel, DNP, ARNP-C, MSCN, and Chief Executive Officer June Halper, MSN, APN-C, FAAN, MSCN, spoke to the vital mission



Megan Weigel, DNP, ARNP-C, MSCN, President of the IOMSN, reflects on the Organization's many achievements over the past two decades, and touches on plans for the future. (Photo credit: The Photo Group)



Moira Baynes, RN, BSN, MSCN (center) after receiving the IOMSN's first LiveWiseMS Award, presented to her by Ms. Halper and Ms. Easterling. (Photo credit: The Photo Group)



Kelsey Lenihan, RN, NP, MSCN, accepts the June Halper Award for Excellence in MS Nursing as Ms. Halper and Ms. Easterling look on. (Photo credit: The Photo Group)

The Johns Hopkins Multiple Sclerosis Center in Baltimore, MD.

Additionally, the IOMSN honored patient advocate Cathy Chester, whose blog – *An Empowered Spirit: Living a Healthy and Vibrant Life After 50* – provides encouragement and practical guidance to people with MS and others. Ms. Chester

received the organization’s Thumbs Up Award, which is given annually to a person or organization who has been instrumental in advocating for and promoting MS nursing.

With next year’s Annual Meeting to be held in Nashville, TN, IOMSN leaders promised an equally festive event to mark the Organization’s 21st birthday, albeit with cowboy hats instead of Mardi Gras masks, and the sounds of Zydeco giving way to the strains of good-ole country music. 🌐



IOMSN members feasted on a variety of New Orleans specialties, some straight from the bayou. (Photo credit: The Photo Group)

Member Profile (Continued from page 5)

though I don’t work with him or see his patients. To be able to surreptitiously eavesdrop on those two when they’re talking to their patients is a huge advantage of being a neurologic nurse practitioner here. There is literally not one day that I dread coming to work. It’s tough, but I love it.”

So does her daughter, Eile (pronounced eye-la), who often accompanies her mother to the office for after-hours and weekend “catch-up work” sessions, and who is a regular companion on the nurse practitioner’s out-of-office patient-assistance ventures. “Eile is a well-known and welcome face around the office, and I love seeing how Dr. Wray’s demeanor changes in her presence. Once, when Dr. Wray had been sidelined from her regular exercise routine by an injury, my daughter ran up to her and Dr. Wray bent down with a huge smile on her face, picked her up, and swung her around!! I told her that the inevitable re-injury better not keep her out of work the next day,” Ms. Lenihan relates, adding that Dr. Wray was back in the office bright and early the next day, none the worse for wear.

One aspect of the work Ms. Lenihan particularly loves is building rapport with her patients. “Especially with new patients who are frightened, beat down, and discouraged, I really want them to trust us. I tell them, ‘We will get you to a better place. In the meantime, you can have a handful of pity parties, but you’re going to have to pull yourselves up by your bootstraps and not let your brain disable you more than the disease does.’”

While Ms. Lenihan devotes much of her time to educating and encouraging patients, she is quick to note that those patients, in turn, have been a great source of education and encouragement for her. She says, “The veteran MS-ers are such a wonderful resource for our practice in terms of being a sounding board for the newer patients. There are so many variations of MS personalities, but all of them are tough. I have learned from them the truth of the phrase, ‘The people that mind don’t matter, and the people that matter don’t mind.’ I also have learned from them that mindset and outlook will set the course for the rest of our lives.” 🌐

