

Letter from the Founding Facilitator for RRNMF Volume 5, Number 2

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In this issue of our journal, we have a number of editorials that we refer to as “What’s on your mind” pieces. Dr. Josh Freeman gives his views on universal health care (he is pro!). Dr. Donald Frey has a wonderful piece reflecting on the adventures of Huckleberry Finn by Samuel Clemens (aka Mark Twain). I have been re-reading all of Twain’s works over the last year and Frey’s views on Twain message struck a chord. Twain in his masterpiece was focused on the humanity and compassion of the relationship between Huck and Jim. I then have two editorials I first sent by email to my team at the University of Missouri about Black History month and Woman’s History month. In the Women’s History month piece, I co-wrote it with Grace Ashraf, a sixth grader on her way to “becoming a physician.”

In the New Stuff category, Pedro Machado, Mazen Dimachkie, and others have agreed to publish the actual protocol, study design, and rationale for the important randomized control trial of arimoclomol in inclusion body myositis. While the study was negative and did not show that arimoclomol could slow the course of progression of IBM, the design of the trial was sound and can be used as a blueprint for future trials. Also under New Stuff is a very nice analysis by Dr. Yuebing Li and his group reviewing the published experience of the new biologic treatments for MG (complement inhibitors and Fc receptor inhibitors) in the setting of myasthenic crisis.

Two cases are published in the Clinic Stuff category. Dr. Conway and colleagues in Cleveland describe a case of paraneoplastic anti-Hu antibody syndrome of jaw dystonia. Drs. Lizarraga and Harada from the University of Rochester and the neuromuscular group describe a case of necrotizing myopathy with anti-SRP antibodies that responded to subcutaneous methotrexate injections when other therapies had failed. And Suzann Beaupark describes a myasthenia gravis case utilizing the Mary Walker Effect to develop a new test to elicit fatigable myasthenia gravis eye signs. Suzann Beaupark, who has myasthenia gravis herself, provides an excellent historical account of Mary Walker’s contribution to our understanding of MG.

In the Looking Back/Looking Forward section, the team behind the neuromuscular update course (directed by Dr. Mazen Dimachkie) publish the next in a series of lectures from the course on the pattern recognition approach to myopathy and neuromuscular junction disorders. In the last issue we published the pattern recognition approach to neuropathy and neuronopathy as well as the laboratory approach to these conditions. We are planning to publish further lectures from this popular course.

In the Other Stuff category, we are grateful that Dr. Michael Abraham has allowed us to publish another of his wonderful poems. This one is titled Culmination. Michael is an interventional neuroradiologist and neurocritical care physician at the University of Kansas Medical Center.

In the Meeting Stuff category, there are two meetings we are highlighting. The first is the recent Festschrift for Dr. Robert Griggs, aka “Berch.” I am publishing the comments I made at the meeting. This was a special event that was put on by the department of neurology at the University of Rochester in Rochester, New York. I am also including the program from this event and some information on Dr. Griggs. The event also marked the delivery of the Dr. Richard Moxley endowed annual lecture, which was delivered by Dr. Griggs. Drs. Moxley and Griggs have been giants in the field of neuromuscular disease and many of us have had the privilege of working with them over our careers. And in the case of Dr. Griggs, to say that I worked with him is an understatement as he truly has been my primary “long distance mentor” for almost 40 years and I talk about some of the ways I have benefited from this mentor-mentee relationship. To be successful you must have good mentors, and I have been very fortunate in that regard.

The second meeting stuff piece is the abstracts, agenda, and welcome comments for the annual Neuromuscular Study Group meeting that is going to be held in Tarrytown, New York on September 20 to 22. This is the 25th anniversary meeting! This year we have an all-time high number of participants and submitted abstracts. This meeting continues to expand and be a major academic highlight of the year where junior and senior neuromuscular clinician researchers gather to discuss progress on their work and develop new projects. A big part of the meeting is the interaction with representatives from industry. With all the major advances in new drugs for neuromuscular disorders, there are more opportunities than ever for the academic clinician scientists and the industry scientists to work together and develop new therapeutic approaches for our patients.

The cover of this issue is a work of art from the University of Missouri Museum of Art and Archaeology. I have been frequenting the museum on the MU campus since I arrived four years ago, and it recently reopened in new digs in the classic Ellis Library on our campus. I am always struck by the gems of art in this small but mighty museum. The work of art on the cover is one of my favorites, even though the artist is unknown. It is a portrait of a woman from the sixteenth century. While the artist is “anonymous,” the museum has enough information to say the artist is a “follower of Pieter Pourbus (Dutch/Flemish, 1523/1524-1583).” The title is simply “Portrait of a Lady.” It was a gift to the Museum of Art and Archaeology at the University of Missouri-Columbia by the Museum Associates in 2015. I think it is an exquisite work of art.

Once again, I want to thank all our authors for submitting manuscripts. And our reviewers and faculty facilitators and student editors. Jiji Oufattole MD has graduated and is now becoming a surgeon. Dr. Oufattole has worked on the journal with me since I arrived at the University of Missouri in 2020. Over the last two years she has served as the senior student editor and has trained the other student editors who are now active in the journal. I cannot thank Jiji enough for the amazing work she has done on the journal for four years. And Lauren Peck, our

undergraduate facilitator, has graduated and will soon be going to school to become a physician assistant. Lauren has also provided enormous help on the journal and review articles. And of course, we are always grateful to Marianne Reed and Eric Bader in the digital publishing unit at KU. We are so grateful to have the publishing platform and their expertise to publish these issues.

Rick