

Letter from the Founding Facilitator, Volume 2, Issue 4

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Welcome back to the [RRNMF Neuromuscular Journal](#) for Volume 2, Issue 4, which opens the fall season. This is the second fall issue where we publish the abstracts of the annual Muscle Study Group meeting. These are at the end of the issue and I have some additional comments to make about the annual MSG meeting preceding the abstracts and messages from industry sponsors of the meeting.

To begin this issue, in the “What’s on your Mind?” section, Dr. Raghav Govindarajan teaches us his 25 steps to diminish diagnostic errors and he cleverly puts them under three categories: “know thy patient”, “know thy test”, and “know thyself.” The next article is by my great friend, colleague and author of ethical topics concerning the practice of medicine, Dr. Josh Freeman. This one comes from one of his blog sites, the [Medicine and Social Justice](#) blog. In this piece, Dr. Freeman gives his views on the complicated issue of parts of the population that are resistant to getting vaccinated for COVID.

In “New Discoveries/New Stuff,” Dr. Melissa Feuerborn publishes a study she began as a medical student at the University of Kansas during the research block between her first and second year of medical school. Dr. Feuerborn is now an intern in internal medicine at the University of Utah Health Science Center. She was interested in Batten’s disease (neuronal ceroid lipofuscinosis) as she was involved in some preclinical research in a mentor’s lab as an undergraduate. During medical school she became interested in how families with children who have Batten’s disease to learn about the disease, the obstacles they face and how well disease-related organizations are doing to support their needs. Dr. Carla Keirns in the History of Medicine Department at KUMC and I helped Melissa on this project. Using the resources of our CTSA supported Frontiers Institute, we connected her with several rare disease community engagement groups. She attended a Batten’s disease conference and spoke to caregivers. She used semi-structured interviews for this process and I believe she did a tremendous job in understanding the interplay between caregivers and these organizations. Also in the “New Stuff” section is an article by Drs. Al Sultani, K. Hafeez, and M. Ubaid Hafeez under the leadership of Dr. Aziz Shabani who report their results of a survey of neuromuscular physicians regarding telehealth versus standard in person patient interactions. They did this survey via the [RRNMF \(Rick’s](#)

[Real Neuromuscular Friends](#)) website, not the journal! However, I am pleased that they are reporting their findings in the RRNMF Neuromuscular Journal. The results may or may not be surprising to you, depending on your opinion regarding telemedicine. The majority of the neuromuscular experts in the survey indicated they preferred in-person patient visits. Based on the experience I am seeing at the Missouri University Health Care (MUHC) system, I suspect this may be true of most physicians. After the near complete use of telehealth visits at the beginning of the COVID pandemic, we are now down to a 10% telehealth visit rate in most of our clinics. I think this is unfortunate and a missed opportunity to change the way medicine is practiced in the United States, and the world, but those are the facts.

In the “Clinic Stuff” section, Dr. Watson and colleagues from Sydney, Australia describe a five year old patient that had both myasthenia gravis and Grave’s disease and review the literature of this association. A pediatric case is unusual.

Also in “Clinic Stuff,” Drs. Isaacoff and Waheed in the Department of Neurology at the University of Vermont Medical Center present a case of an adult with a GBS-like illness who is found to have a renal cell carcinoma (presumed.. no biopsy) and serum antibodies to contactin-associated protein-like 2 (CASPR2) and leucine-rich glioma inactivated proteins (LGII). In addition, on EMG, there was evidence for peripheral nerve hyperexcitability. The authors do an excellent job in tying these pieces together and reviewing the interesting new literature on these auto-antibodies.

Drs. Fathi and Nafissi from the Neuroscience Institute at the Tehran University of Medical Sciences report an interesting observation that myotonic dystrophy patients can have a Beevor sign. Initially described by Dr. Beevor as a sign of a thoracic myelopathy below T10, it has also been described in some muscle disorders such as facioscapulohumeral dystrophy (FSHD), GNE myopathy, inclusion body myositis and Pompe disease but only in one case previously with myotonic dystrophy type 1; here is a second case. We are so glad to have submissions from our physician colleagues in Iran.

In the “Looking Back/Looking Forward at Stuff” section, Dr. Murala and her colleagues at the University of Missouri, Columbia review sleep disorders in amyotrophic lateral sclerosis (ALS). And finally, the last section has abstracts from the MSG meeting which will be held virtually on October 1-3, 2021.

In “Other Good Stuff,” we are so pleased to have Dr. Michael Abraham, a neurologist at the University of Kansas Medical Center, submit another of his wonderful

poems. This one is called “Hamilton Awakening.” Keep them coming, Michael! You are a true Renaissance physician.

The cover of this issue is by a tremendous artist, Jessica Wohl. This portrait of an elderly man is called “Raymond” and I believe it was painted in the early 2000s when he was living at the Village Shalom facility in Overland Park, Kansas. I purchased it at an art auction at the Epstein Art Gallery in Village Shalom not long after she painted it to raise money for the gallery and institution. It has been one of my favorite pieces and whenever I have guests in my home they are drawn to the painting as it portrays the honorable progression into old age so well. Jessica relocated a number of years ago to Kentucky, where she continues her art work in a variety of mediums.

I emailed her and got her permission to publish the photograph. I believe the man in the painting has deceased.

Lastly, a quick postscript from the amazing diptych painting we published on the cover of Vol 2, Issue 3 by Vincent Valdez. Vincent is one of the major artists in the United States and he still works out of San Antonio, Texas. He was thrilled that we used a photograph of his paintings which I had purchased almost 20 years ago. When I sent him a copy of the RRNMF Neuromuscular Journal, he corrected me on the titles I used for the diptych. The title for both pieces together is “Ah yes, the notorious place everyone speaks of.” The other title refers to the original lithograph; the blue painting is based on, “Yo Soy-ee Blaxican”. An image of that print is below:

