

## What's In This Issue?

Letter from the Founding Facilitator for  
Volume 3, Issue 1

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This is the first issue of volume 3! An exciting milestone in the history and life of a new periodical. We have packed a lot of great content in this issue. Along with this piece in the *What's on Your Mind?* category is another wonderful article by Dr. Josh Freeman called *Brooklyn Nostalgia* from his blog. It is a beautiful piece of writing. Then, in honor of Black History Month (February 2022), I wrote about Dr. Charles Richard Drew, a true pioneer in the field of blood product transfusions. This first came out in one of my "Messages from the Executive Vice Chancellor for Health Affairs" at the University of Missouri in a shorter format.

In the New Stuff category, there are a number of articles on myasthenia gravis. Dr. Gloria Ortiz-Guerrero and colleagues at KUMC (and myself from my time at KUMC neurology) analyzed the results of repetitive stimulation testing on a cohort of MG patients. Dr. Ortiz-Guerrero did this study as a resident and fellow. Dr. Bakri Elsheikh and THE Ohio State University neuromuscular team (my neuromuscular alma mater!) performed a depression screening study in a group of MG patients.

Also from THE Ohio State University, Dr. Jonathan Morena reported on thirty zero-negative MG patients and their clinical features. Dr. Mukaish Kumar, along with Dr. Raghav Govindarajan and Wei Huang (all at the time at the University of Missouri) developed an Empathetic Neurological Care-structured evaluation and they then measured empathy in both American medical graduates and international medical graduates.

Also in the New Stuff category is an article that is first authored by Dr. Beladakere, a neurology resident at the University of Missouri, describing the effect of 3,4-Diaminopyridine phosphate (DAAP) in SOD ALS mice. The experiments were performed by our colleague Dr. John Stanford at the University of Kansas Medical Center and were meant to support our team's efforts to do a randomized control trial of DAAP in ALS patients. To cut to the punchline, unfortunately the DAAP in SOD mice study did not show a benefit compared to placebo. To compliment this article,

In the Proposed Stuff section Drs. Raghav Govindarajan, Stanley Iyadurai, and the KUMC/MU team are publishing a valiant attempt to get an NIH-funded DAAP in ALS study. And not only was the proposed use of DAAP in ALS novel, we also proposed a novel trial design named Efficacy

and Effectiveness Too (EE2). In EE2 studies, a phase three efficacy randomized control trial is nested in a larger effectiveness study. In the effectiveness portion of the study, ALS patients are enrolled who do not meet the stricter entry criteria for the efficacy study are randomized to DAAP versus placebo as well. The idea is to see how the drug works in a larger population. So even if the efficacy study meets statistical significance, the study also asks whether that is also the case for a larger group of ALS patients, and if not, is there a trend? This is a very interesting concept I learned from Dr. Harry Selkar at Tufts several years ago at one of the CTSA (NIH clinical translational science award) meetings we attended. He helped me understand the concept and set up brainstorming groups through the NCATS CTSA program for our team in Boston, which was very enlightening. So we put together this proposal for a EE2 study for DAAP in ALS to NCATS, and it did not get funded. Since the SOD DAAP study was negative we did not feel quite as terrible compared to our other grant rejections! Nevertheless, just because an animal study is negative, or positive, of course does not mean a human study will be negative, or positive! But they often do inform one another. And to my knowledge, the NIH has still not funded a true EE2 study. In essence an EE2 study is designed to not only answer a question about whether drug is effective in a homogenous study population (FDA Phase 3) but also in the wider population, the latter being an FDA Phase 4 study approach.

In the Clinic Stuff section there are a number of fascinating cases. Dr. Tim Fullum just finished his neuromuscular fellowship at KUMC and that group wrote up an interesting case of mononeuropathy multiplex due to lymphatoid granulomatosis. Dr. Ramin Khodabandehlou from the Amman Clinic in Tehran, Iran sent us a case of leg amyotrophic diplegia and reviewed the LAD literature. Dr. Kumar and the University of Missouri team wrote up a case of Guillian-Barre syndrome in the setting of COVID-19 infection and reviewed the literature. And Drs. Helena Hwang and Jeffrey Elliot at University of Texas Southwestern in Dallas describe an interesting and rare paraneoplastic syndrome with weakness and a low phosphorous that is tumor-induced or oncogenic osteomalacia.

In the Other Stuff section, we are publishing several beautiful poems. One called *Boots* is by Michael Stanley, MD, a neurology resident at the Massachusetts General/Brigham Neurology program. Dr. Stanley sent this poem to the journal last year in hopes it could come out for Veteran's Day. I am sorry we did not get it published in time for Veteran's Day but it is a lovely poem that can be appreciated

at any time. When Dr. Stanley submitted the poem he wrote us the following:

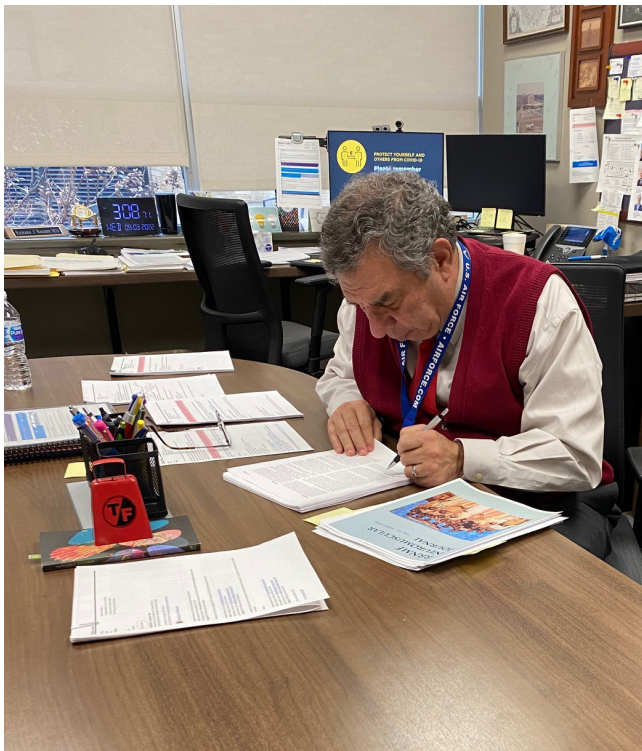
“I’m offering for submission to your journal a narrative poem about a neurological injury (among them phantom limb) suffered by a veteran explored through the telling of his beloved cat. I thought it would be a good fit for the November edition of your journal, considering Veterans Day falls in November, and after a year of the COVID campaign it is time to cherish the heroes of wars medical as well as military”. Thank you, Dr. Stanley for submitting this poem.

Two veteran poets and neuroscientists, Elizabeth Rowe, PhD and Vernon Rowe, MD have once again sent us poems of theirs for this issue. And they have two more they sent me for an upcoming issue, so stay tuned.

The cover is another amazing painting by Jessica Wohl who has been featured on the cover of Issues 4 and 5 in Volume 2. This piece is called “Wedding Picture”. As I said when I showed her paintings on the cover of Issue 5 from 2021, she had photo albums of her family’s wedding pictures from the 1960’s and 1970’s. I think the paintings from Issue 5 may have been 1960’s and the current very large work of art is from a 1970’s wedding, from the fashion and hairstyles! This is a very large work consisting of six canvas paintings, each roughly three by four feet so the composite work is

about nine by eight feet. When we moved into our home in Columbia, Missouri, we had a wall in the vaulted living room that I knew would be a perfect fit for this painting. I had remembered seeing it at a Crossroads gallery in Kansas City at a First Friday art walk many years ago. I emailed Jessica if she had ever sold it and she had not. I guess finding a home for a piece this large can be a challenge. I told Jessica “I will buy it!” Jessica shipped the painting to Kansas City and my friend and artist Jorge Garcia cleaned it up (it had been in storage for over a decade) and he then brought the painting(s) to Columbia along with a scaffold and he and a colleague expertly hung this beautiful and complex work of art in our living room. The wedding party is on one big wall, and they are looking at paintings on the opposite wall that were on the cover of Vol2/Issue 5: “Smile for Grandma” and “Erwin at the Buffet Table”. Thank you, Jessica, for allowing us to publish your paintings for the covers of the journal.

I would like the readership of the journal to know that we are now the official journal of the Muscle Study Group. This was approved by the MSG Executive Committee last fall. We are also of course the official journal of Rick’s Real Neuromuscular Friends! Therefore, we have now indicated this on the page where we list all the facilitators and other information about the journal.



Rick editing Volume 3, Issue 1.

