

## Message from the Founding Facilitator for Volume 5, Issue 1

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Welcome to the first issue of 2024: Volume 5, Issue 1. Here is what is in this issue:

Two excellent editorials from our recurring authors regarding problems facing our health care delivery systems and society in general. Drs. Josh Freeman and Donald Frey are both leaders in family medicine and former chairs of departments of family medicine. Dr. Freeman discusses how and why the number of primary care physicians is falling, in part due to inadequate reimbursement, and he gives some ways the Center for Medicare and Medicaid Services (CMS) could provide some relief for this problem. Dr. Frey takes on the issue of the national minimum wage and asks, “what does it take to make a living wage?”

In the *New Stuff* category, our colleagues at the University of Iowa and the Iowa City Veterans Affairs Medical Center compared demographic, treatment, and survival data on ALS patients from the Iowa VA Medical Center with data published by other ALS clinics across the US and Europe. They conclude that the length of survival of patients in the VA clinic was comparable to these other multidisciplinary clinics. They also conclude that multidisciplinary clinic care provides better outcomes than care in general neurology clinics. Their data also suggests that edavarone may provide some survival benefit for ALS patients. A second manuscript on ALS comes from three leaders in the field: Dr. Bedlack at Duke, Dr. Heitzman in Dallas, and Dr. Sheffner at Barrow Neurologic Institute in Phoenix, AZ. They asked ALS clinicians to complete a survey regarding their attitude on which FDA approved drugs should be used in ALS patients and rank the barriers to getting patients on each drug. Clinicians also provided responses regarding the need for prior authorizations and denials and delays in getting prescriptions approved. They conclude insurance barriers are the main reason preventing large portions of ALS patients who should be taking edavarone and sodium phenylbutyrate/taurursodiol from actually being on these medications, and other useful insights facing clinicians and ALS patients. The final manuscript in the *New Stuff* section is by the University of Kansas neuromuscular group and myself and describes a pilot study of phenylbutyrate used in inclusion body myositis. We were able to demonstrate that phenylbutyrate is tolerated and safe in this population of patients and hope this pilot study will lead to a larger randomized controlled trial.

In the *Clinic Stuff* section we publish two nice case reports. One is from our colleagues at UT Southwestern, led by Dr. Bhai (one of the journal's associate facilitators) and

his team that included several students (Ahmad, Govil, and Modi) and describes a case of rhabdomyolysis and exercise intolerance in a middle-aged man. They present the case as a diagnostic problem that posed key questions, to which they uncover answers. The elegant work-up ultimately reveals the diagnosis of McArdle's disease. We were pleased to receive a manuscript from India by Drs. Sankalp Mohan and Megha Dhamne which describes two cases that raises the quandary of distinguishing between acute and chronic inflammatory demyelinating polyneuropathy.

Finally, in the *Looking Back/Looking Forward* section we publish two rather unusual review articles that emanated from a longstanding course on neuromuscular disease that I have been involved in with Drs. Mazen Dimachkie, Todd Levine, Jonathan Katz and, more recently, David Saperstein. We began conducting this course “on the road” many years ago and delivered it dozens of times throughout the USA and Canada. During COVID, we naturally switched the course to Zoom, where it has remained. The course was recorded, and these are the first edited “transcripts” along with figures that cite the power point slides we used in the course. When you read these reviews, envision one of the authors delivering this as a lecture, which is how it was originally presented. It is conversational, in the first person. The first lecture is titled “Pattern Recognition of Neuropathy and Neuronopathy: 7 Questions / 11 Patterns.” I first developed this pattern recognition approach to neuromuscular disease in the 1990s. Over the years we have made some modifications and, in this version, we have expanded the approach from the prior 6 questions / 10 patterns. To paraphrase the great William James, MD who said, “The rivalry of the patterns is the history of the world,” the talk concludes “The recognition of the patterns is the key to understanding neuromuscular disease.” The second review is on the laboratory approach to testing in neuropathy and neuronopathy and emphasizes that one must start with the clinical pattern, which will guide the clinician in deciding the laboratory tests to order. All the course teachers are equal authors on these publications and, at any given time, any of the authors could deliver one of the dozen lectures, so we hope to continue publishing further review articles based on course transcripts. This course has been an exciting journey for all involved. We hope that by publishing these lectures we can make them available to a wider audience in a meaningful way. Finally, I would like to thank Lauren Peck, a student at the University of Missouri, who has served as the undergraduate student editor for the journal and who provided immense help in manuscript preparation for these course publications.

For the cover art in this issue, I have chosen the famous painting Vincent van Gogh painted of his bedroom at Arles – “The Bedroom At Arles,” 1888. His bedroom is so simple and in many ways heartbreaking. A true classic of art.



RRNMF Neuromuscular Journal facilitators meeting prior to publishing Volume 5, Issue 1.

Richard J. Barohn, M.D, Facilitator In Chief and Founding Facilitator; Yuebing Li, M.D., Associate Chief Facilitator; Salman Bhai, M.D., Associate Chief Facilitator; Jiji Oufattole, Managing Editor Facilitator; Himavarsha Kincharla, medical student facilitator; Michael Sherby, medical student facilitator; Alexandria Spurgeon, medical student facilitator; Marianne Reed, publishing facilitator; Eric Bader, publishing facilitator.

Not pictured: Michael T. Pulley, M.D. Ph.D., Associate Chief Facilitator; Farrell Landwehr, medical student facilitator, Lacey Raper, medical student facilitator