

## What's In This Issue?

Letter from the Founding Facilitator for  
Volume 3, Issue 2

Richard J. Barohn, MD

The current RRNMF Neuromuscular Journal issue, volume 3/issue 2, marks the two-year anniversary of this new and innovative communication vehicle. We have come a long way. Thanks to all the facilitators (editors) and reviewers, and authors. This journey has been both educational and fun, and I am looking forward to the third year of this journal.

In this issue, in the “What's on Your Mind?” section, we have many articles of interest. One is a piece I wrote honoring Dr. Jane Cooke Wright during African American history month for my Executive Vice Chancellor message at the University of Missouri. Dr. Wright was an oncologist, and her father was also a distinguished cancer physician. They were a cancer-fighting team. She was a pioneer in using methotrexate for cancer, a drug we use in neuromuscular disease to this day. Dr. Josh Freeman provides his thoughts on being a physician specialist from a family practice doctor's perspective. I thought it would be a good piece for our ultraphysician specialist's neuromuscular group to read.

Another well-known and respected family physician, Donald Frey, has contributed a piece he wrote: an imaginary letter from the Chinese Communist Party to the People to the American people! Like Dr. Freeman, Dr. Frey is a retired physician who has a fascinating blog site called “A Family Doctor Looks at the World” ([afamilydoctorlooksattheworld.com](http://afamilydoctorlooksattheworld.com)). Check this site out for Don's other blog pieces, and we may publish more in this journal.

Two other pieces in this section are very moving and personal. In the last issue, we heard from Marci Gibson, who has ALS and who I have known for nearly 30 years since she developed symptoms of the disease as a young adult. In this issue, her father, Harold, discusses the many frustrations the family has encountered in communication devices for Marci. Harold is an engineer, and over the last several decades, he has had to be very creative to develop a communication system that allows Marci to continue communicating with the world. To say we need more time, effort, and money to develop modern and more

effective communication devices for those who lose the motor ability to speak is an understatement.

The other extraordinary piece in this section is by the artist Dylan Mortimer. I have known Dylan for about a decade. He has cystic fibrosis, and he has undergone two lung transplants. His medical odyssey inspires his art, and he explains this better than I can attempt to in his article.

The cover of this issue has two recent paintings by Dylan that I purchased from him (remember always to support the artist whose work you appreciate and enjoy). One is an IV bag full of stuff, and one is of many colorful pills. In the past, Dylan has also created vast works of art over 60 feet long that have been installed in buildings in Kansas and Missouri. One large piece of work is in the Health Education Building at KU Medical Center. We have inserted a few of these pictures at the end of this piece and the end of Dylan's.

In the “New Stuff” section, our colleague Dr. Mazen Dimachkie, with the support of CSL Behring, provides a wonderful discussion about subcutaneous immunoglobulin for CIDP. Also, in new stuff, Dr. Avdagic and colleagues at the University of Missouri focused on diagnosing and misdiagnosis of CIDP from a series of 20 patients.

In the “Clinic Stuff” section, the MIZZOU team, Molly Shipman, a medical student, and Dr. Govindarajan describes a lumbosacral Plexopathy due to an internal iliac artery aneurysm and reviews the literature. From the University of Kansas, Dr. Mai Yamakawa, a neurology resident, and Dr. Mamatha Pasnoor present a case of Vasculitis neuropathy and myelopathy. Drs. Abhiram Bhashyam and Salman Bahai (from Orthopedics at the Massachusetts General Hospital and Neurology at the University of Texas Southwestern Medical Center, respectively), discuss a very interesting case of a patient with transient shock symptoms while cycling under a power line- or biking induced kinetic electrical micro shocks-BIKE! Who knew? And the same Boston-Texas team used a case to illustrate the approach to evaluating an elevated creatine kinase and provide a nice algorithm diagram.

In the “Proposed Stuff” section, our large team is publishing a grant we wrote for PCORI that did not get funded. The grant is called BEAT CSPN and stands for Determining Best of Inferior Drug(s) Using an Adaptive Platform for Cryptogenic Sensory Polyneuropathy. This was an extension of our prior PAIN CONTROLS comparative effectiveness

research study (CER) of CSPN that compared nortriptyline, duloxetine, pregabalin, and mexiletine. In BEAT CSPN, we proposed a CER to randomize CSPN patients to six different drugs: gabapentin, topiramate, valproate, venlafaxine, levetiracetam, and lacosamide. We all thought it was a great idea. The study section did not. So, we are publishing the proposal and the critiques for others to learn from, and perhaps someone else will take this idea and run with it in the future.

Finally, in the “Other Stuff” we again are honored to have poems by Elizabeth (Betsy) Rowe PhD and Vernon (Bud) Rowe MD, who are poets inspired by their science and medical background.

Enjoy this jam-packed and exciting issue of the RRNMF Neuromuscular Journal. And once again, thanks to all who continue to make this unusual publication and communication platform possible.

Rick



Dylan Mortimer, left, and Dr. Richard J. Barohn pose with Mortimer's artwork titled “So Fresh, So Clean.”