

What's In This Issue?

Letter from the Founding Facilitator for Volume 2,
Issue 5

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This is the final issue of Volume 2 for the year 2021. To open Issue 5/Volume 2 we have three additional pieces (in addition to this founding facilitator introduction) in the “What’s on Your Mind?” section. The first is from a woman with ALS named Marcie Gibson. Marcie has been a patient of mine since 1994 when I diagnosed her with ALS at age 23. I asked her to write an article about her journey with ALS. Her journey has been remarkable, and she provided a wonderful piece of writing. Next is another terrific article from Dr. Josh Freeman’s blog. From the view of a family medicine doctor, Dr. Freeman discusses the controversial FDA approval of the new drug for Alzheimer’s disease, which was made over the objection of the FDA advisory panel. Next, I wrote my recollections of how the practice parameter on thymectomy for myasthenia gravis (MG) was developed. This was prompted by an email from a neuromuscular fellow, Nicholas Brennecke at Case Western University in Cleveland in which he asked me to provide the “backstory” about the practice parameter. I don’t know how he knew I had a backstory, but I did! Thanks for asking me, Nic. I have located my original proposal to do a thymectomy study that I wrote in 1993 with Carlyne Jackson MD, and I have included this and the MG scales we developed in the “Proposed Stuff – Old Stuff” section.

In the New Stuff category Dr. Li and his group in Cleveland report their positive experience using methotrexate for MG. This case series made me smile since we failed to show the superiority of oral methotrexate over placebo for MG in a randomized controlled trial. The Cleveland experience adds to other anecdotal reports about the benefit of methotrexate in MG. Dr. Mamatha Pasnoor and I are not prepared to give up on proving this benefit and we recently submitted a federal grant to use subcutaneous methotrexate for MG. Wish us luck. We realize we are in an amazing age in the treatment of MG in which we have complement inhibitors and soon we may have neonatal Fc receptor blocking drugs for MG. These options are, amazing breakthrough drugs but they are extremely expensive, and it will be great if we can show an inexpensive drug can be effective in MG patients who are still symptomatic when they are on prednisone. Also in the New Stuff section is a nice manuscript by Dr. Brill and other MG experts along with their partners at Argenx in which they surveyed neurologists in the United States about practice patterns for approaching MG. This information was presented in

September at the MSG meeting. The third New Stuff paper is really old stuff and describes the results of static fatigue testing in a group of MG patients. I say this is old stuff as it is data we collected at UT Southwestern in the 1990s when Dr. Wolfe, Laura Herbelin, myself and others were all partners in the MG clinic. This is data we never published but as a collector/hoarder that never throws out anything, I had saved all of the data and Dr. Wolfe had one of his sharp residents, Dr. Lail, put this paper together. So, the New Stuff section in Issue 5 is all MG.

The Clinic Stuff contains three articles. One is a case of acute motor and sensory axonal neuropathy (AMSAN) in the setting of immune thrombocytopenic purpura and Hemophilus influenzae by Drs. Satyasi, Ahmed and Farheen. Another is an interesting case of an adult with Becker muscular dystrophy who also had Covid-19, reported by a group at University of Missouri, Columbia. Finally, there is a case report from the University of Kansas Medical Center group of necrotizing myopathy with a rash following Covid-19 infection and vaccination.

In the “Other Good Stuff- Art Stuff” section is a wonderful poem by Thomas Trevor and Dr. Hani Kushlaf written from the perspective of a patient with inclusion body myositis (IBM). Thomas has IBM and Dr. Kushlaf is a neuromuscular physician. The other piece are lyrics to a song that Walter Anderson wrote called “AINT NO SENSE PROJECT (BOY IN THE BACK SEAT)” that was inspired by Dwight Jones who was recently released from prison in California after serving 21 years of a life sentence for a crime he did not commit. Walter’s daughter, Adrian, is a newly minted attorney who works for the Loyola Project For the Innocent who was instrumental in obtaining his release from prison.

Finally, in December we held the annual Kansas City Consortium on Musculoskeletal Disorders (KCMD) at the University of Missouri-Kansas City (UMKC) campus. This annual event is sponsored by four universities: UMKC; University of Missouri-Columbia; University of Kansas Medical Center; and Kansas City University (the region’s osteopathic medical school). It is a lively meeting in which science is presented from the neuromuscular and musculoskeletal fields. This year we once again had a number of interesting presentations, many by students. KCMD has a pilot grant program for investigators from these institutions who want to collaborate across university lines on research and several of the presentations were a result of these projects. I am pleased to be able to publish the abstracts from this meeting.

Our cover this month is again from the wonderful artist Jessica Wohl. We had a painting of hers on Vol 2; Issue 4 that is in my collection and on this issue are two more. The

pink painting is called “Smile for Grandma” and the blue painting is called “Erwin at the Buffet Table”. I saw these in the early 2000s at a gallery event in the Crossroads area of Kansas City on a First Friday event. I initially purchased the grandma painting from Jessica because the woman reminded me of my grandmother (I think she looks like many grandmas!) Jessica told me she painted a series of paintings inspired from a 1960s wedding photo album in her family. The “Erwin” painting was from that series as well. Later I purchased the “Raymond” painting at a Village Shalom art auction that was on the cover of Vol 2, issue 4. All are up on the walls in our house in Columbia, Missouri now and they have been great favorites of folks viewing the collection. I have one or two more of Jessica’s I may put on the journal’s cover with her permission.

As we close 2021, I want to thank the authors and facilitators who have supported the journal. I also want to thank our outstanding medical student editors Breanna Tuhlei and JiJi Oufattole, our undergraduate journal assistant Lauren Peck, and of course our outstanding KU digital press team of Marianne Reed and Eric Bader. I appreciate all of you so very much. Happy Holidays and Happy New Year.

Rick