

## WHAT'S ON MY MIND

## Letter from the Founding Facilitator

Welcome to Volume 1/Issue 2 of the RRNMF Neuromuscular Journal. I think you will enjoy the content of this issue and I am pleased that we are getting a number of submissions to the new journal. As in the first issue, this issue has a collection of original articles (New Stuff), single case reports (Clinic Stuff), a review article (Looking Back Stuff), and an imaging article (Visual Stuff). In addition, we have the “answer” with references from the Visual Stuff piece in Issue 1.

There are two articles in the New Stuff category. Dr Govindarajan and his colleagues at University of Missouri-Columbia report their experience with using edavarone in ALS. This is a retrospective report but provides good data. Eventually we need prospective data in the form of a comparative effectiveness study in a real world situation (not a pharmaceutical company driven trial) in which patients are put on edavarone with or without riluzole or riluluzole alone. Until then these retrospective clinic experiences are important. Our KUMC group led by Dr. Mamatha Pasnoor looked at a group of patients with CIDP by various criteria and then determined response rates to IVIG based on if they met one of the published criteria. The bulk of the work on this project was done by Charles (Drew) Roach when he was a medical student at KUMC. Drew is now a neurology resident at Washington University in St Louis. Well done, Drew!

The two cases in Clinic Stuff are very interesting. One is again by the Columbia, Missouri group and the first author is Sara Hooshmand They report a case of scapuloperoneal myopathy and cardiomyopathy that has a novel myosin heavy chain mutation. Family history suggested an autosomal dominant disorder. The simultaneous co-occurrence of the heart and skeletal muscle involvement is unusual. The second Clinic Stuff is an unusual GBS variant case seen by Felix Chang and Jon Katz and they consulted with Gil Wolfe and myself on it a number of years ago. For some reason, the case was not published and so I encouraged the group to submit it to our new journal. The patient had bilateral ptosis, so from this standpoint it was one of the GBS variants originally described by Dr Ropper. There was no extremity weakness but the patient did complain of tingling in the extremities and some mild difficulty swallowing. But additionally the patient had limb myokymia clinically and by EMG in the first dorsal interosseous muscle and he complained of involuntary movements of the fingers that

came on suddenly with the bilateral ptosis. The authors believe this extends the phenotypic spectrum of this GBS variant.

The group from then Department of Neurology at the University of Columbia was a big contributor to this issue as Drs Digala, Haider and Govindarajan also supplied a nice review article (Looking Back Stuff) on various neuromuscular causes of weakness in the ICU setting. Drs Merchant and Twydell in Grand Rapids Michigan submitted a dramatic image in Visual Stuff showing an infiltration access in the pectoral is minor and gluteus minimus muscles due to tuberculosis. And Dr Shabani gives us the answer on the Videos he published last month!

Finally, we have an amazing cover in which we show a painting in the Metropolitan Museum of Art that is a Rembrandt self portrait as a young man. We obtained the image from Creativecommons.org. We plan on having an art image on every issue cover.

Please give us feedback on this new journal. And please submit articles. I promise we will provide a hassle free and friendly peer review process by our Facilitators (e.g., editor/reviewers).

I would like to thank our KU Digital Publishing Services staff who are helping me enormously as we launch this new publication: Marianne Reed who leads the group and Pam LeRow. We could not get these first two issues out without their help.

Rick

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*The following are my farewell comments to the KUMC research Community on my retirement from KUMC in May 2020.*

## HALE AND FAREWELL COMMENTS

By Dr. Barohn

Dear Colleagues,

In February, I announced that I accepted a position as Executive Vice Chancellor for Health Affairs for the University of Missouri Health System at the University of Missouri-Columbia and will be leaving the University of Kansas Medical Center after nearly 20 years of service.

I want to extend a sincere thank you to the University of Kansas Medical Center community for the opportunity to serve and lead in several capacities, including as Chairman of the Department of Neurology, Vice Chancellor for Re-

search, President of the Research Institute, and Director of Frontiers: University of Kansas Clinical and Translational Science Institute. It has been an honor to work alongside some of the brightest and most dedicated faculty and staff at KU Medical Center.

As a result of the commitment to excellence by so many of you, KU Medical Center is now a major clinical and translational research leader in the United States. I am very proud of what we have achieved together. I have spent most of my academic career at KU Medical Center and will always have a special place in my heart for this institution and the many outstanding colleagues with whom I have worked.

I am confident that Matthias A. Salathe, MD, will provide a steady hand at the helm of the KU Medical Center research enterprise as the Interim Vice Chancellor of Research. As a nationally recognized leader in pulmonary disease, Dr. Salathe has done an amazing job in rejuvenating the research program in the Department of Internal Medicine. His strong leadership and dedication to research will be tremendous for this institution.

I am also assured that the future of clinical and translational research at KU Medical Center and in the Kansas City region is in good hands as Mario Castro, MD, MPH, is set to take over leadership as Director of Frontiers. Dr. Castro, also a highly regarded pulmonary research physician in the Department of Internal Medicine, is the Director of the Rainbow Clinical and Translational Science Unit. I look forward to hearing of the wonderful things to come from Frontiers under his leadership.

I am very excited to begin my journey at the University of Missouri. It is truly amazing that I've been given an opportunity to make a significant impact at another academic medical institution at this stage in my career. I feel extremely fortunate for the honor to be part of KU Medical Center and the University of Missouri.

I am grateful to so many of you at KU Medical Center—fellow faculty, researchers, clinicians, administrators, staff, residents, fellows, and students—and hope to personally express my gratitude to many of you before I leave on Friday, May 8, 2020. Unfortunately, I may have to reach out via telephone or Zoom due to the current COVID-19 situation. However, I will only be two short hours away in Columbia, Missouri, and will undoubtedly be back in Kansas City of ten. Please keep in touch.

With appreciation,



Rick

*The following is my message to the graduating medical students at the University of Missouri-Columbia School of Medicine in May 2020. This was both a hale and farewell as I was really introducing myself to these graduating doctors.*

## GRADUATES OF 2020

What a pleasure it is for me to address your class on this big day. I am the incoming Executive Vice Chancellor for Health Affairs and in this role I will be working closely with Dean Zweig and Jonathan Curtright, the CEO of MU Health Care, to move our enterprise into the next decade. While I am arriving at the same time that you are graduating from the medical school, what we both have in common is that we are entering a new phase of our medical careers. Of course you are just entering the most dynamic and gratifying part of your careers as you become a physician and can make an enormous impact on individual patients and society. I, on the other hand, am beginning a new path late in my career, and I hope I can still have an impact on health care delivery and research and education. But I envy you as you are taking the first steps as physicians. There are so many challenges and opportunities that are literally just around the corner for all of you. And in the next few years you will have an exponential growth curve as a physician in both your knowledge base and in your skills as you embark on the journey to become a mature physician. I know the training which you have received at this great medical school will serve you well in this journey. Dean Zweig and I look forward to hearing from you in the years to come. Please check in and let us know where your journey has taken you. The main advice I would like to give you as you begin the path as a physician is to always regard every patient you encounter with empathy and make an attempt to connect with them as a fellow human being and not just as a patient. In this very odd covid era many of us have been seeing our patients on zoom. I have been doing a zoom telemed clinic for three years for ALS patients that live in rural Kansas. It is amazing to me how much we can do as physicians remotely through this technology. And I am repeatedly struck by how grateful the patients are for the connection that can still be obtained via telemed. And it occurred to me during my last telemed clinic in Kansas City last week that it works because the patients can feel that I am truly concerned about them no matter if I am holding their hand in person or looking at them directly through a monitor. After all of the knowledge and skills you learn in medical school and residency and fellowship, I really believe that what is the most important is the empathy you show your patients in every encounter. Having empathy will not only make you a better physician but will make your journey a labor of love. Thank you for allowing me to be a part of this most important day.