

Welcome Letter from Michael K. Racke, MD



Dear Friends of the Foundation of the CMSC:

Heading into this **holiday season**, we at the Foundation of the CMSC are especially grateful for you, our supporters, for all of your contributions to the world of **multiple sclerosis** care this year. Our mission to support the **multiple sclerosis** workforce of the future takes on additional meaning in this season of giving as we think of all the ways we have benefited **MS** patients across the globe, as the holiday season leads to reflection on what one has achieved through the course of the year. Our impact on patients and their families cannot be overestimated.

Contributions to the Foundation have come in steadily this year as always, and we encourage you to keep FCMSC in mind when planning your yearly giving. This edition of **Pillars** features an article highlighting a few easy social media/internet-focused ways to contribute to our programs and to support our overall mission.

In other Foundation news, we are busy planning our activities for the 2019 Annual Meeting of the CMSC, which will take place in Seattle, Washington from May 28th - June 1st. In addition to our usual networking and learning opportunities, we will be hosting yoga/meditation class early Friday morning to ensure that your day begins on a peaceful, mindful note. We have already applied for and received support for these initiatives and look forward to bringing some FCMSC-style "Namaste" to your meeting experience.

On behalf of the Foundation and all those involved in bringing the **Pillars** newsletter to you each quarter, I want to wish you and yours all the best this holiday season and in the new year. Thank you for your continued support and feedback, which helps us improve each and every year. We hope 2019 brings continued happiness to you and your family. **Happy Holidays!**

Best Regards,



Michael K. Racke, MD
President, FCMSC Board of Trustees



Focus on FCMSC Programming: Mental Health Mini-Mentorship



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In response to a national shortage of mental health practitioners knowledgeable about neuropsychological disorders in **MS**, the Foundation has turned to a format with which we have had considerable success in different disciplines in the past: **the Mini-Mentorship Experience.**

We have identified two host sites for the pilot version of this program: the **MS Center** at Holy Name Medical Center, in Teaneck, New Jersey, and Neuropsychology Associates of Fairfax in Fairfax, Virginia. It is our hope that this pilot program, in which individuals in early stages of their career are chosen to participate in a one-week intensive mentorship experience consisting of thirty-five hours of immersive training in the psychological impact of **multiple sclerosis**, will be renewed and expanded in the coming years. For the pilot program, we are placing two individuals at a time in each facility. We anticipate that there will be two sessions in each facility, for a total of eight participants in this first iteration of the program.

This week-long training forum will provide mental health professionals including social workers, psychologists, and psychiatrists, with new information about the unique mental health challenges faced by persons living with **multiple sclerosis**, screening strategies for recognizing the presence of mental health issues, and best practices for mental health care to maximize outcomes for this population. In addition, we will address the need for promising professionals-in-training to receive both expert mental health mentorship and a view of the career path options open to them. Experienced and engaged **MS** mentors will offer not only clinical information but personal advice on building and managing an **MS** career. Questions such as, "what is the difference between clinical information and personal advice?" and "how can a focus on mental health in the **MS** community ultimately benefit those affected by this disease in the future?" will be addressed in the course of the experience.

The program will pair veteran practitioners in **multiple sclerosis** mental health care and research with professionals who are contemplating a focus on multiple sclerosis mental health care, or are 1-3 years into their specialty careers. Mentors will share their knowledge and experiences with their **MS** Mental Health Mini-Mentorship Forum Trainees over the course of the five-day mentorship experience and at the Annual Meeting of the CMSC in May 2019 in Seattle, Washington.

This program was conceived after lengthy discussion about the prevalence of mental health problems in the **MS** patient population, and the paucity of professionals with sufficient clinical experience with this cohort. Full funding for this program has been obtained from EMD Serono; however, as of press time additional funding opportunities are still available for this important endeavor.

FCMSC medical students' fellowships lead to the discovery of new biomarkers of disease activity and response to therapy in multiple sclerosis



In 2014, I was visited by a medical student who wanted to work in my lab. His name was Adam Kruszewski (pictured left.) He wanted to become a neurologist, and multiple sclerosis (MS) was a disease that interested him. At that time I was interested in finding biomarkers of disease activity and response to therapy in multiple sclerosis, and identifying these markers was a project that had been waiting for a new student or fellow for a while. In MS, early diagnosis and appropriate, timely therapeutic intervention are critical factors in ensuring favorable long-term outcomes. Identification of markers that could predict disease activity and response to therapy would allow for intervention strategies that might prevent progression of the disease. One problem in MS is the lack of a test to help identify which patients had responded to therapy. Often, treatment was started, and then a trial and error process over time determined the treatment course.

Adam was awarded a fellowship by the FCMSC to support the project. Adam was instrumental in identifying three potentially useful blood-based biomarkers of relapse and of the response to glatiramer acetate (GA) treatment (RGC-32, FasL, and IL-21) in patients with relapsing-remitting multiple sclerosis (RRMS), which is the most frequent subtype of MS. All three of the studied biomarkers are known to play an important role in cell survival.

In our study, the probability of accurately detecting acute relapse (acute worsening of the disease) was 90% for RGC-32, 88% for FasL, and 75% for IL-21. The probability of accurately detecting response to glatiramer acetate treatment was 85% for RGC-32, 90% for FasL, and 85% for IL-21. These findings of Adam's were published in *Experimental and Molecular Pathology* 2015, 99:498-505.

Adam has overlapped in my lab with another outstanding medical student, Daniel Hewes, (pictured right.) Daniel has joined Adam in investigating another possible biomarker of disease activity, SIRT1. SIRT1 (a member of the sirtuin family) was one of the genes that we found to be regulated by RGC-32. SIRT1 is an enzyme involved in the removal of acetyl groups from proteins (deacetylation) and is involved in regulating a number of cellular processes, including transcription, metabolism, DNA repair, and aging. To my delight, Daniel's proposal was also funded by an award provided by the FCMSC MS Workforce of the Future program. Adam and Daniel were able to show that during relapses, MS patients have a significantly lower expression of SIRT1 mRNA than do stable MS patients. These results were published in *Experimental and Molecular Pathology* 2017;102:191-197.



About the time Daniel's data were ready for publication, Jonathan Ciriello (pictured left) joined my lab; he was willing to continue Daniel's project. Daniel did the first experiments to see whether the phosphorylated and active form of SIRT1 can also be used as a biomarker of disease activity and response to therapy. Daniel and Jonathan found statistically significantly lower levels of p-SIRT1 protein ($p < 0.0001$). Jonathan was also supported by a fellowship award provided by FCMSC MS Workforce of the Future program. All this work would have not been possible without the help and dedications of other members of my lab and I want to mention Cosmin Teglia, Dallas Boodhoo and Alexandru Tatmir.

Our aim is to take these results further and expand these results to a randomized, controlled trial, with the goal of tailoring treatment at the early stages of RRMS. This work by medical students, which has led to three publications, would have not been possible without the support received from the FCMSC MS Workforce of the Future program, and it shows how important the program is for generating and nurturing the next generation of leaders in MS research.

Horea Rus MD, PhD
Professor of Neurology
University of Maryland,
School of Medicine,
Department of Neurology

Easy Ways to Support the Foundation of the CMSC in 2019

1. Through Amazon Smile: AmazonSmile is an initiative operated by Amazon with the same products, prices, and shopping features as Amazon.com. The difference is that when you shop on AmazonSmile, the AmazonSmile Foundation will donate 0.5% of the purchase price of eligible products to the charitable organization of your choice. Every item available for purchase on www.amazon.com is also available on AmazonSmile at the same price. You will see eligible products marked "Eligible for AmazonSmile donation" on their product detail pages. On your first visit to AmazonSmile, simply search for "Foundation of the Consortium of Multiple Sclerosis Centers" and select us as your choice to receive donations from eligible purchases before you begin shopping. Every eligible purchase you make at smile.amazon.com will result in a donation to FCMSC.

2. Through Facebook Fundraisers: Facebook is an amazing tool to connect with people from all phases of our lives, and has enabled many of us to keep in touch with people we would never otherwise be in contact with. One feature we as a nonprofit particularly love is the Facebook Fundraising tool. Anyone can set up a fundraiser at any time and ask friends to donate to a preferred cause; this year, we encourage you to set up a birthday fundraiser benefiting the FCMSC. This is a quick and easy way for those who wish to acknowledge your birthday to donate a few dollars to a cause that is meaningful to you! Go to <https://www.facebook.com/fundraisers/> to get started.

3. Direct Donations Through Friends of the Foundation: By becoming a Friend of the Foundation, you can help us meet our goal: creation of an expert cadre of skilled and committed healthcare professionals who are trained to provide the very best in comprehensive care and research for the thousands of people living with MS now and in the future. With your contribution, which you may designate as a tribute to a family member, friend or colleague, you become a Friend of the Foundation. For more info go to: <http://cmscfoundation.org/friends-of-the-foundation/>



Foundation of the Consortium of Multiple Sclerosis Centers
info@cmscfoundation.org
3 University Plaza Drive, Suite 116, Hackensack, NJ 07601
(201) 487-1050
www.cmscfoundation.org

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