



National  
Multiple Sclerosis  
Society

**MS Learn Online  
Feature Presentation  
MS and the African American Community: Research, Clinical Trials and  
Reasons for Hope  
Featuring Mary Hughes, MD and Walter Royal, MD**

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**>> Dr. Royal:** So, Mary, why would you say an African-American should participate in a clinical trial?

**>> Dr. Hughes:** Well, that's a good question, because historically, and we're both aware that people have had concerns and very legitimate concerns about participating in trials. Our memories are long, the Tuskegee Syphilis experiment was not that many years ago, and as you know, that was a study that really wasn't a study, it was looking at how African-American men live with syphilis even though there is treatment.

The reality is is that we really learned, and that there are so many safeguards that have put into place that those things should never happen again. The biggest reason I challenge people who are African-American to participate in trials is that if we don't participate, we won't be able to answer the questions about what's the best approach.

We use the example of high blood pressure. We know that we approach how we treat high blood pressure by taking into account ethnicity, that we know there's certain treatment approaches based on race, and we really need to be able to answer that question for multiple sclerosis. We don't really participate in the trials, we can't really look at how we respond-- if we respond differently.

**>>Dr. Hughes:** Have you had any of your patients participate in any of the trials that have been recruiting African-Americans?

**>>Dr. Royal:** Yes, yes we have. We have-- a large of our percentage of our patient population who is African-American, and many do come to our center looking to participate in clinical trials, and I think that is reflective of the fact that the word is

getting out there very effectively that it is important for African-Americans to participate in clinical trials.

**>>Dr. Hughes:** Yes, and I think that this is exciting to see patients participating in trials that are really at genetic factors, but also participating in treatment trials, so that we can better answer the question about how people respond, and if there's a difference based on ethnicity, so the more recent trials, the pill studies are always exciting, I think are doing a better job of having people who are African-American enroll in those trials.

**>>Dr. Royal:** I would agree and even with the better participation that we're seeing, it's important for even more patients to inquire about participating in clinical trials we've seen in other diseases, where that's had a great impact in improving treatment for not just African-American patients, but all patients, and it would be great to see the same for MS.

**>> Dr. Hughes:** You know, I've really found a lot of the information coming out of genetics exciting when we're talking about MS, and the unique contribution that African-Americans are really making in that regard to how we understand MS.

**>> Dr. Royal:** I would agree that it's a really exciting time when it comes to the genetics of MS and understanding the disease in African-Americans, as well as in other racial and ethnic groups. Generally, when one thinks about a genetic study, they think that it really involves understanding what the disease is doing in that individual. In fact, African-Americans have a very unique opportunity to make a contribution that affects the entire population of patients with multiple sclerosis.

**>> Dr. Hughes:** You know, in other diseases, genetics have been able to predict how someone responds, and so, that's a potential for it.

**>> Dr. Royal:** So, the information that has been obtained so far not only has identified specific risk factors for developing multiple sclerosis, but also genes that can be protective, not just in African-Americans, but, again, potentially in other populations as well.

**>> Dr. Hughes:** So, while there's a lot of information coming out about African-Americans and MS, there are a couple of ways to look at it. Some people would say that it's potentially discouraging, that the literature does support that MS in African-Americans may be more aggressive. On the other hand, if we start to identify risk factors, that we may be able to intervene in the future, we may be able to solve some

of these challenges that we're faced with today. So, knowing a problem, understanding a problem, hopefully in the end will help us solve the problem faster.

>> **Dr. Royal:** That's-- I would agree with that.

>> **Dr. Hughes:** I'm going to ask you a question. I know you must get this one often. When I finished with my visit, and we finished talking about the FDA-approved medicines for MS, then I start getting the questions over the over-the-counter or the barbershop solutions. How do you address that with your patients?

>> **Dr. Royal:** Well, first of all, I encourage my patients to be very open in asking about the various other therapies that can be available, the alternative therapies. It's important to know from a standpoint that some of these treatments can interact with various medications that are proved to treat multiple sclerosis, and patients have to be aware of that as well.

Also, there are some alternative approaches that could be quite beneficial, and it's important for a patient to understand how to pursue them, how to go on them, so to speak, in a way so that it's not detrimental for their MS.

And I can't say that I'm an expert when it comes to all of these different therapies, so that knowing that a patient has that question can be a sign to me that that individual needs the information, and it may mean referring that patient to someone who does have expertise in that area.

>> **Dr. Hughes:** I'm glad to hear I'm not the only who-- I know I don't have all the answers, and a lot of times, that does make me look things up or refer them on, but what is certainly encouraging is having those open lines of communication. I want to know about it first, and then have a chance to discuss either the risk or the benefits, or what we don't know about it, so that the patient can make the best-informed decision they can.

You know, when I first went into the field of MS, African-Americans weren't talked about at all, and, really, 1994, when the optic neuritis treatment trial and subgroup analysis was done, I think that's really the first memory I have of talking about "Is there a difference in course," and what an amazing change it has been over the last 10, 15 years, and now that we've gone from suggestions that there may be a difference to actually trials that are really targeting, looking at the genetic differences, so I think that's certainly is an important change over my career that really has-- it's a reason for hope.

>>**Dr. Royal:** I would agree. The increase in the amount of information that's available, the impact that it's had on how one treats not just the general MS population, but also African-Americans with MS, has been great to see over the past 15 years or so. Certainly, when I got into this business, African-American patients were very frustrated with their disease, and were more likely to be told that it was all in their head, or not to necessarily be treated as aggressively as their white counterparts, so to see this focus on African-American patients not only in the amount of new information that's being generated, by it being translated into just a higher level of quality of care, has been really exciting and gratifying.

>>**Dr. Hughes:** Walter, I've enjoyed this opportunity to be able to talk to you about our shared interests in African-Americans in MS, and I will use some of our insights when I go back to the office, with my patients. So, I appreciate the opportunity to talk to you.

>>**Dr. Royal:** Thank you very much, and I will certainly do the same.

>>**Dr. Hughes:** If you would like to become involved in the activities of the National MS Society, please go to [nationalmssociety.org](http://nationalmssociety.org). This is Mary Hughes for MS Learn Online. Thanks for joining us.