Pediatric MS: Specialized Care for a Unique Population
5 questions with …
Deborah Miller, PhD, LISW

Dr. Deborah Miller is a researcher at the Mellen Center for Multiple Sclerosis Treatment at the Cleveland Clinic, and Associate Professor of Medicine at the Cleveland Clinic Lerner College of Medicine of Case Western Reserve University. Her research interests focus on relationship and family adjustment to MS.

1. What research are you currently working on?
   We are working to better understand what access people with MS have to health insurance, short & long term disability, long-term care, and life insurance. We want to determine how often people with MS change insurance, the concerns they have getting, keeping or not having insurance, and what happens to their well-being because of those concerns.

2. Why did you want to work with NARCOMS?
   The NARCOMS participants are a diverse group of people living with MS and they are really committed to helping researchers gain a better understanding of their experiences.

3. What area of research needs more attention?
   Depression is a significant cause of disability and we need to understand the combination of treatments that are most effective, and develop more effective ways to deliver that care.

4. What do you think will be the next breakthrough?
   I believe that it will be finding an effective treatment for people living with progressive MS.

5. What is your “MS Tip” to managing a life with MS?
   As a patient recently told me, “I focus everyday on making a place for MS in my life, while making sure that I keep MS in its place.”
Letter from the Director: Celebrating 20 Years of Data Collection

NARCOMS Info Corner

Feature Focus: Pediatric MS Centers; Researcher Studies MS as NMSS Top Scholar

MS Apps: Men Living (and Writing) With MS

Survey 101: MS Medications

Q&A: NARCOMS & Clinical Trials

NARCOMS Messenger

MS Reflections: Social Cognitive Correlates of Physical Activities in African-Americans with MS

Snapshot: Diagnosis & Symptoms

MS News: Ocrelizumab Shows Promise in PPMS; Fatty Acids Protective Against MS?

Play: Deck the Halls!

Faces of NARCOMS: Moving Forward, Not Looking Back!

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Teva Neuroscience

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Greetings,

“Happy Birthday to us, happy birthday to us, happy birthday to NARCOMS!”

That’s right—this year, 2016, marks the 20th anniversary of NARCOMS! For those of you who have been with us from the start—we can’t thank you enough. For those who’ve filled out surveys for 5, 10, 15 years or more, we salute you. And for the newer participants, we look forward to your many years of contributions! The information you have provided is invaluable to building a longitudinal research base, which in turn can be used by researchers to advance their work in finding treatments, and ultimately a cure, for MS.

Throughout the year, we’ll be looking for ways to mark this important milestone. We’re starting the year off with a look at the US network of pediatric MS centers, of which there are only a handful nationwide. Officially established in 2006 by the National Multiple Sclerosis Society, the original six centers have since expanded to nine—and the work they do is crucial. We take a closer look at the unique challenges and opportunities offered by working with patients with MS under the age of 18. We talk to one young researcher, Ashley Haynes, who recently became one of only 10 students in the U.S. named a 2015 Top Scholar by the NMSS.

This issue’s “MS Reflections” focuses on the limited research on exercise and physical activity in African Americans with MS. Since this population experiences, “a more aggressive disease course, elevated risks of comorbid conditions, and poorer prognosis with disease modifying therapies,” authors Rob Motl, PhD, and Dominique Kinnett-Hopkins, PhD candidate, suggest additional focus should be placed on developing physical activity interventions in African Americans with MS.

“MS News” brings research presented at the latest European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) congress. This includes the promising results of a Phase III clinical trial, called ORATORIO, on a drug called ocrelizumab in Primary Progressive Multiple Sclerosis. NARCOMS enjoyed a robust research showing at the conference, meeting with some of the world’s top investigators conducting MS research. Don’t forget to browse our Clinical Trials listings for the latest opportunities to participate.

As mentioned in “Messenger,” NARCOMS now has a presence on Instagram, the photo-sharing social media site—@narcoms_now. Please follow us on Instagram and Twitter as we continue to build our presence and conversations in this space. Happy holidays to everyone and we hope you are looking forward to the New Year with as much excitement as we do!

Best,

Dr. Robert Fox
Managing Director, NARCOMS
NARCOMS INFORMATION CORNER

Have an idea?

We would love to hear from you!
Send us your questions, comments & suggestions.

Call: 1-800-253-7884 (toll-free US)
Email: narcomsnow@narcoms.org
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Who you’ll hear on the phone:
Chad or Chasity

NARCOMS Promise

Your personal information is always confidential.

The NARCOMS Global MS Patient Registry facilitates multi-center research on multiple sclerosis, developing collaboration between MS centers of excellence throughout the world to increase knowledge, improve clinical care, and enhance the quality of life for persons with MS.

View Past Surveys

Go to: www.narcoms.org

Click on: Participant Log in Here

Enter your username and password.
Select the correct picture, click Login.
Click the Form Summary link.

Choose the survey you would like to view from the drop down menus and click the View Summary link.
Print like you would any document.

En Español

Para acceder a nuestro sistema a línea:

www.narcoms.org/es
Nuestro sitio de web es de alto seguridad a para su confidencialidad.

Para solicitar la envío de un cuestionario de inscripción por correo, llame al Registro NARCOMS al (800) 253-7884.

Become a part of NARCOMS:
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Reminder When Completing Paper Surveys:

Please use pen rather than pencil when filling out NARCOMS paper surveys. Responses are scanned to electronic files for data capture and pen is easier to read. Thanks!
While multiple sclerosis (MS) is considered a rare disease, it does affect several hundred thousand adults in the United States and more than two million persons worldwide. In children, however, MS is even less common. The National Multiple Sclerosis Society suggests 8,000–10,000 children under 18 in the United States have MS.

Adult-onset multiple sclerosis is typically diagnosed between the ages of 20 and 50. In the last five years, treatments for adults with relapsing remitting MS have advanced dramatically, including the approval of several oral therapies. Pediatric MS remains a challenging diagnosis and while no treatments are approved for use in children, several of the disease-modifying therapies used in adults are used in children off-label. Children who are diagnosed with MS need appropriate care throughout their lifespan.

MS centers dedicated to the care of children are relatively few in the United States. In 2006 the National Multiple Sclerosis Society (NMSS) issued a request for applications (RFA) to fund a network of pediatric MS centers. Several clinician-researchers; centers not awarded to those who did research without clinical care at the University of Alabama at Birmingham (UAB) submitted an application and received the funding to start the UAB Center for Pediatric Onset Demyelinating Disease (CPODD). It was then, and remains, the only pediatric MS center in the southeast.

Since it opened in 2006, the center’s clinicians have treated more than 400 patients. Roughly one-third have MS, one-third have transverse myelitis or neuromyelitis optica (NMO), and one-third have acute disseminated encephalitis myelitis (ADEM). The CPODD primarily treats patients from Tennessee, Texas, Georgia, North and South Carolina, Louisiana, Florida, and Mississippi.

“We wanted to have a seamless transition for MS patients from pediatric to adult care,” says Khurram Bashir, MD, neurologist and co-director, UAB Center for Pediatric Onset Demyelinating Disease (CPODD). “We chose the center’s name with the idea that we would not only be seeing MS patients, but also [patients with] other conditions which overlap with MS.”

The clinic initially evaluated patients only one half-day per month. As the patient population has grown, the hours have expanded to two full days each month.
The center staff include pediatric and adult neurologists, rehabilitation staff, radiologists, urologists, ophthalmologists, nurse practitioners, and mental health professionals. “Everyone sees the patients, depending on what their needs are,” Bashir says. “We’ve been able to improve diagnosis and treatments.”

From a patient perspective, everyone who comes to the clinic sees Bashir, who is an adult neurologist, in addition to the center’s pediatric neurologist, Dr. Jayne Ness. “When they turn 19 and have to transition care to an adult neurologist, they come to my clinic. I’ve already seen them and know their history, and the problems they have,” says Bashir.

Confusion is often one of the first symptoms reported in younger children, which can be a symptom of ADEM.

“Younger kids will get ADEM, then optic neuritis, repeatedly,” says Ness. Relapses in pediatric MS can be far apart. Numbness and other symptoms present really early and get “passed off for a long time,” Ness says, “especially in pediatrics, where people assume that kids are generally healthy.”

Ness, who did her residency and fellowship both at UAB School of Medicine, says they saw the need for the pediatric clinic when they realized that no one really knew what was happening to pediatric MS patients in the long-term.

“At that time, we only had four drugs available to treat MS, period. None were approved for use in children—we were scared to use them in kids,” Ness recalls. Today, several therapies are used off-label in pediatric patients, Bashir says.

Who Gets It?

Though the race and sex distribution varies by region, the pediatric MS population in the southeastern US is mostly female and “disproportionately African-American,” Ness says, at a rate of about half of all patients. The rates of pediatric NMO patients who are African American are even higher, she says.

In the nearly 10 years since it has been operating, the UAB CPODD has seen almost 500 children; approximately 60% are from Alabama and the rest are primarily from other states in the Southeast. Most are referred to the center by pediatric neurologists in other states. Only a handful of patients—5 percent, Ness says—have MS.

What does MS in Kids Look Like?

Most children presenting MS symptoms are teenaged, or post-pubescent. The first symptoms with which they present are similar to those in adults: weakness or numbness in one limb, vision loss or double vision.
A Visit to the Clinic

So what is different about a visiting a pediatric MS center? “Our clinic visits can be long, but that’s because we might only have one chance to speak with these families,” Ness says. The patient’s primary care practitioner may be out of state, so the CPODD staff takes care to provide as much information as possible to those providers.

A strong point of emphasis is the importance of letting kids tell their own stories—about their symptoms, treatments, and experiences—rather than letting caregivers do all the talking.

“We have them practice telling their story to someone new,” Ness says. “These kids grow up and go off to college and have to transition to looking out for themselves. We teach them certain words to use to get attention, or get what they need.”

In addition, the clinic offers educational programs, spearheaded by Yolanda Harris, RN, MSN, MSCN, and nurse practitioner with UAB Pediatric Neurology.

Harris started working at the center shortly after it opened and calls herself, “a partner in caring for children with MS.” She emphasizes how little information is widely available about pediatric MS, and how concerning it was to see how patients felt about living with the disease.

“We don’t know how this disease will impact these children long term,” Harris says. “New treatment modalities (options) will put a different spin on pediatric versus adult MS.”

Harris says that developing brains need to be monitored for any cognitive changes and detrimental effects of long-term MS treatments.

Harris also stresses the need for additional research, and mentions a few studies coming out on the use of disease modifying therapies (DMTs) on pediatric patients. “We explain to patients and their parents that while these drugs haven’t been studied in kids, specifically, we’ve been using them for 15 years, and there are enough data to show they can be safe.”

Regarding the new oral therapies now available to adults with relapsing-remitting MS, Harris suggests while she might try one in an older patient (17–18), she would not do so on a younger patient until further research and trials have been conducted because of the potential safety concerns.
Nine years ago, Yolanda Harris and colleague Sarah Dowdy, MPH, research coordinator for the CPODD, devised a retreat for the center’s patients and their families.

“With pediatric MS, it’s so rare, your next door neighbor won’t know what you’re talking about,” Harris says. She says the limited clinic time is often insufficient to teach patients and their parents all they need to know about the “life changing diagnosis they’ve just been given.”

The CPODD Family Retreat will celebrate its tenth anniversary in 2016, with a three-day camp, taking place June 2–5, at the Children’s Harbor facility on Lake Martin in Alexander City, Alabama. The camp is open to any child who has been seen at the CPODD center and has NMO or MS. It is a chance for families and caregivers to come together in a relaxed setting to hear presentations on treatments, physical therapy, mental health resources, and complementary and alternative therapies such as yoga and water aerobics. It is free for attendees, supported by grants and fundraising events taking place throughout the year. (For more information, visit: www.childrensharbor.com.) Children who have graduated past the eligible age for camp attendance can return to volunteer as counselors and mentors.

“It’s worth the work to put it all together each year when you see families have that sigh of relief on their face,” Harris says, “because until you’ve met somebody who’s dealt with what they’ve dealt with, they think they’re the only ones. It’s invaluable seeing these kids make friends that will last them a lifetime. It allows us the opportunity to get out there and clear up any misconceptions the families might have.”
Looking Ahead

Many neurologists working with pediatric MS patients say they love their work because they can always learn something new on the job. The ongoing challenge, they say, is making the transition from pediatric to adult MS care a smooth one. MS clinics such as the CPODD and others around the country work to facilitate this process by integrating teams of caregivers whose expertise spans the patient’s life. (Meticulous recordkeeping doesn't hurt either, Ness says.)

For a complete listing of NMSS Pediatric MS centers, including mailing addresses, phone numbers and contact emails, please visit:

www.narcoms.org/narcomsnow/nmsscenters

RESOURCES

Natural History of Multiple Sclerosis Symptoms
ncbi.nlm.nih.gov/pmc/articles/PMC3883021/

Multiple Sclerosis Association of America’s review of Pediatric MS research at ECTRIMS 2015
mymsaa.org/news-msaa/1370-ectrims-2015-summary

National Multiple Sclerosis Society—Pediatric MS:
www.nationalmssociety.org/What-is-MS/Who-Gets-MS/Pediatric-MS

Pediatric MS Centers:
tinyurl.com/j2qz23v

Pediatric MS Support Network:
tinyurl.com/jowwhjm

United States Network of Pediatric Multiple Sclerosis Centers
www.usnpmsc.org/clinicalcenters.html

Go to www.clinicaltrials.gov and search “Pediatric Multiple Sclerosis” for a more complete listing of ongoing research in pediatric MS
Ashley Haynes embodies the spirit of young investigators who will make a difference in the lives of those with multiple sclerosis. Haynes is a senior in college close to finishing her undergraduate degree in biomedical sciences at the University of Alabama at Birmingham. This summer, Haynes received word that she had been named one of only ten 2015 National Multiple Sclerosis Society Top Scholars.

“Growing up, I witnessed everything that happened to them,” she recalls. “I went to their doctor’s appointments with them, and just being by their side and witnessing how cruel this disease can be sometimes inspired me.”

Haynes, who comes from a town of fewer than 1,000 residents in rural Alabama, attended a community college before she learned about the Center for Pediatric Onset Demyelinating Disease (CPODD) at the UAB. She applied to transfer to UAB to complete her bachelor’s degree, and emailed the CPODD clinic to come down and shadow its employees.

“Being from a rural town, I have always thought about doing primary care. I always knew I wanted to do research, after watching my mother and grandmother live with MS,” she says. “I never knew about the pediatric clinics for MS until I came to UAB.”

Since the summer of 2014, Haynes spends time helping out however she can in the clinic, collecting paperwork and trying to distract the kids who are there for their often-lengthy appointments. Haynes says she hopes to take a gap year off after graduation and conduct an internship while waiting to see whether she gets into the UAB School of Medicine, where she hopes to study to become a neurologist.

“Working in the clinic has pulled me closer to neurology, especially with an interest in pediatric and adult MS,” she says. “I think some of the neurologists we have here at the CPODD are some of the most inspirational, the best.”

Haynes encourages kids living with MS to see a pediatric neurologist and visit a pediatric MS clinic if they can.

“They should go to a doctor that they feel like they can take their brave face off for, and be comfortable talking about what is really going on,” Haynes says.
It is with profound sadness that NARCOMS reports the passing of a giant in the world of multiple sclerosis (MS), JOHN F. KURTZKE. Dr. Kurtzke was a pioneering neuroepidemiologist and Professor of Neurology at Georgetown University who is best known for his creation of the Expanded Disability Status Scale and for his research on MS. After graduating from Cornell University Medical College in 1952, Dr. Kurtzke started his career in the field of neurology as Chief of the Neurology Service at the Veteran’s Affairs (VA) Medical Centers in Coatesville, PA, from 1956 to 1963, and then in Washington, DC, from 1963 to 1995, where he became Professor of Neurology at Georgetown University, where he was Professor Emeritus.

Most of Kurtzke’s work deals with MS. In particular, he is widely known for his Expanded Disability Status Scale or EDSS, a method of quantifying disability in MS, and for his pioneering work in the field of neuroepidemiology, a branch of epidemiology he helped to establish in 1967 with Dr. Len Kurland and Dr. Milton Alter.

The author of more than 200 peer-reviewed articles, Kurtzke has received several awards including the 1999 Charcot Award by the Multiple Sclerosis International Federation, the 1997 Dystel prize for MS research awarded by the American Academy of Neurology, and the Lifetime Achievement Award from the Consortium of Multiple Sclerosis Centers in 2003.

In 2009, the Consortium of Multiple Sclerosis Centers (CMSC) and the American Academy of Neurology Foundation (AANF) have created the John F. Kurtzke, MD, FAAN, Clinician-Scientist Development Three-Year Award, a jointly-sponsored fellowship in MS research, “to honor the contributions of Dr. Kurtzke and inspire new MS healthcare professionals to follow in his path.”

Kurtzke will be remembered and honored for his commitment to MS by the CMSC each year during the John F. Kurtzke Memorial Lecture that will open each Annual Meeting starting in 2016. He will be missed by all who follow in his footsteps.

We’re proud to be celebrating the 20th anniversary of data collection in NARCOMS. The registry was founded in 1993 and began to collect information from participants like you 20 years ago, in 1996. In 2016, we’re looking forward to celebrating this milestone in collaboration with the 30th Anniversary of the Consortium of Multiple Sclerosis Centers (CMSC).

We could not have reached this important anniversary without your help and dedication to MS research! Look for 20 years of NARCOMS news throughout out 2016 in NARCOMS Now, at www.narcoms.org, on Twitter, and Instagram. Thank you from all of us at NARCOMS for being a part of our Registry!
MS APPS (& BLOGS)

This installment of MS Apps & Blogs features several blogs about MS written by men. MS occurs in men at a ratio of about 1:2, or one man to every two women.

Matt Cavallo
http://mattcavallo.com/category/blog/

Matt Cavallo was diagnosed with relapsing-remitting MS when he was 28. He updates his blog regularly with stories about his life with MS. Cavallo compares his symptoms and personal experiences to what he has researched and read about MS. He encourages others living with MS to share their stories, through tales of his own on tough topics such as parenting with MS.

Richard Cohen – JourneyMan
richardmcohen.com/journeyman

JourneyMan is the blog of author and journalist Richard Cohen, husband of TV personality Meredith Vieira. Cohen had a 20-year career in network television news. Today he writes articles for outlets such as The New York Times and WebMD, and in 2004 published Blindsided, a book chronicling his dual diagnoses of MS and cancer.

Cohen’s blog “JourneyMan” is frank and open about his ongoing frustration with MS, and his attempts to see the bright side of aging, coping with symptoms, and more.

Travis Gleason – Life with Multiple Sclerosis

This Everyday Health blog, Life with Multiple Sclerosis, is the voice of chef, author, and food journalist Travis Gleason. In addition to his prosaic food writing and preparation, Gleason also happens to have MS. He was diagnosed in 2001, and began writing about MS along with his other passions. An active volunteer with the National MS Society, Gleason discusses his work and life with MS, including accommodations he may have to make to travel to an MS leadership conference, or the cost of his MS drugs.

Dan and Jennifer Digmann
http://danandjenniferdigmann.com/

This last blog comes from a couple, both with MS. Dan and Jennifer Digmann each have different forms of MS, and met at an MS support group. They’ve been married 10 years, and together write about their lives as MS advocates.

Not every post tackles MS, but their down-to-earth tone makes their writing easily accessible to anyone.
Chronic diseases like MS can be treated with many different types of medications — some that are designed to change the course of MS, and some that will help with only the symptoms of MS. Both types of medications are included in NARCOMS surveys:

1. **MS Therapies:** Also called MS treatments, immunological therapies, and disease modifying therapies or DMTs. These medications are not a cure for MS, but DMTs can reduce the number and severity of relapses for those who have them. DMTs can also slow down the damage caused by relapsing MS that builds up over time. This is asked at enrollment and in every update survey.

2. **Symptomatic therapies:** These medications treat the symptoms of a disease but not the cause. That is, they help treat the pain that can be associated with MS but will not help the cause of the pain. This is asked at enrollment and in some update surveys.

**Why should you answer these questions?**

Even if you are not taking any medications to help your MS, it is important to answer “No,” rather than simply skipping the questions. Skipping the questions does not mean NARCOMS will assume you do not take any medications — your answer will be treated as missing.

By answering “No” (and not skipping the question), your data will be included in research that compares people that do and do not use medications. If you skip the question then your information can not be used in those research projects.

**How to answer these questions:**

- If you are not taking any of the medications, answer “No” for the main questions that will ask “Have you taken any of the medications listed in the prior 6 months” and then move onto the next question.

- If you have taken any of the medications listed, please check “Yes” and then select the specific medications you have taken how long you have taken the medication according to the instructions given.

**If you ever need help or have questions about the medications included, please do not hesitate to contact us!**
**Q:** What is the difference between NARCOMS and a clinical trial?

**A:** NARCOMS is what is called a registry or observational research study. In observational studies, the participant (that is you!) is measured or tells the researchers (that is NARCOMS!) how they are doing, what medications (if any) they are taking, and answers other important questions. Observational studies can involve visits to doctors or other health-care providers. NARCOMS is a self-report registry (you provide all of the answers) and does not involve any in-person assessments.

In clinical trials, participants are assigned to treatments (such as medications, diets, or exercise programs) and then are followed to see how they respond. These research projects usually involve in-person visits with clinical measures such as MRIs, lab tests or other procedures. Clinical trials can also include some self-reported measures.

Clinical trials are designed to answer specific questions about a treatment: Does the new drug work to improve an MS patient’s condition, or is one drug better than another drug? These trials tend to be more costly and therefore shorter, in terms of follow-up time, than observational studies.

Registries and observational studies provide some of the only information on longer term outcomes in people with MS. Thanks to YOU and your participation, NARCOMS has as much as 20 years of follow up on some of you—which is so important in answering questions about a long-term, chronic disease like MS.

**Q:** Can I participate in both NARCOMS and clinical trials?

**A:** Absolutely! In fact, in the Spring 2015 update, 27% of participants reported that they have participated in at least one clinical trial since their MS diagnosis.

In addition to the NARCOMS semi-annual updates that you receive in Spring and Fall each year, NARCOMS helps researchers to tell you about clinical trials in two ways:

1. Every issue of *NARCOMS Now* contains information on current clinical trials (see page 22) in which you might be eligible to participate, and how to find out more information about those studies.

2. NARCOMS works directly with researchers conducting clinical trials to notify NARCOMS participants that they may be eligible for those projects. **NARCOMS never gives out your contact information** to these researchers. You will receive a letter or an email if you may qualify for any of these projects, You can choose whether to participate.

To submit a question for Q&A please email - narcomsnow@narcoms.org
NARCOMS at ECTRIMS

NARCOMS enjoyed a robust research representation at the recent European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) 31st annual congress, held in Barcelona, Spain, October 7–10. In all, NARCOMS researchers, including Dr. Ruth Ann Marrie, Dr. Bob Fox, Dr. Gary Cutter, Dr. Amber Salter and Dr. Stacey Cofield, presented five posters featuring research based on NARCOMS data. Their topics included:

- “Differences in Use and Perceptions on Effectiveness of Marijuana for MS: A Survey of NARCOMS Participants”
- “Quantitative Comparison of MS Patient-Reported Injection Site Reactions and Flu-Like Symptoms with Non-Pegylated and Pegylated Subcutaneous Interferon Beta Drugs in NARCOMS”
- “Shared Decision Making and Disease Modifying Treatment History in NARCOMS”
- “Characteristics of Continued Tecfidera Use in the NARCOMS Registry”
- “Social Media and Recruitment in the NARCOMS Registry”

As publications result from the research presented in these, we’ll highlight them in future issues of NARCOMS Now.

Numbers from the congress are impressive:

- 9,022 attendees from 96 countries—claiming to be the world’s largest research conference dedicated to multiple sclerosis
- 1,899 abstracts
- 1,300 posters
- 94 oral presentations
- 1,044 Contributors who tweeted using #ECTRIMS2015 – including NARCOMS!

We also represented NARCOMS in the exhibitors’ space with a booth explaining our programs and encouraging new enrollment and continued participation.

NARCOMS Twitter Poll

Thank you to everyone who has taken part in our poll to determine the look you prefer for our Twitter account. You can still vote online at www.narcoms.org/twitter-poll or Tweet us your preference.

Twitter is one way we keep you posted about events, news, and conferences we’re covering. Tell your friends we’re here @NARCOMS and thanks to all who’ve followed us in the last few months!

NARCOMS on Instagram

Did you know NARCOMS is now on Instagram? We’ve launched our account, @narcoms_now, and encourage you to follow us! We’ll be sharing our photos from conferences and events we take part in, research-related messages, magazine highlights, and other news worth touting. Wondering why we don’t follow your personal account?

To best maintain our participants’ privacy, our social media policy is to follow only MS- and neurology-related organizations and prominent public figures and/or clinician/caregivers pertaining to multiple sclerosis. Please follow us today!
**NARCOMS Now 2016 Cover Art Contest!**

This year marks the 20th Anniversary NARCOMS data collection and the 5th year of *NARCOMS Now*!

We want to celebrate by including YOUR art on the 2016 NARCOMS Now covers for Spring, Summer, and Fall!

**To submit your original artwork, email a high resolution photo to:** msregistry@narcoms.org

One piece will be featured on each remaining cover for 2016 and all submissions will be shown online at www.narcoms.org/narcomsnow

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**Winter 2016 Cover Image: SEA CHANGE**  
**Artist:** Claire Corman

**Website:** www.clairecorman.com

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**About the Artist:** Claire Corman is located in Birmingham, AL, the home of the NARCOMS Coordinating Center, and is known for her abstracts of landscape. Using brushes, knives, fingers, and anything else within reach as tools, the paint tells its own story through shape, color, texture and composition. Her works have been featured in lifestyle magazines including *Cottage Living* and *Coastal Living.*
Physical activity may provide substantial benefits for those living with MS\(^1\). However, evidence suggests that persons living with MS do not engage in sufficient amounts of physical activity, and subsequently miss out on the potential benefits\(^2\). Much of the research regarding physical activity in MS has focused on Caucasians, and consequently physical activity guidelines, programs and interventions have been developed for this segment of the MS population. African-Americans living with MS experience a more aggressive disease course, elevated risks of comorbid conditions, and poorer prognosis with disease modifying therapies, providing considerable reason for focusing research on African-Americans with MS\(^3,4\). To date, researchers have not directly compared physical activity rates in African-Americans with Caucasians, nor considered factors that can be targets of behavior change programs. Such information is essential for health behavior change among African-Americans with MS.

Dominique Hopkins, a doctoral student at the University of Illinois at Urbana-Champaign along with Robert Motl, PhD, conducted a study that compared physical activity levels between African-Americans and Caucasians living with MS by use of questionnaires and social cognitive theory (SCT) that considers personal, behavioral, and environmental factors associated with a change in health behaviors (Figure 1).

Through NARCOMS, 287 African-Americans and 287 Caucasians, matched by sex, age, degree of disability and location, were invited to participate in the study. The questionnaires included information on demographic and clinical characteristics, physical activity, exercise self-efficacy, function, social support, exercise outcome expectations, and exercise goal setting and planning.

Of the 574 people that were recruited, 151 African-Americans and 185 Caucasians elected to participate. The majority of respondents were Female (86.0%), with differences between African Americans and Caucasians in marital status, income, and current disability level on the PDDS (Table 1).

African-Americans living with MS reported lower physical activity levels, greater functional limitations, and lower expected benefits of physical activity than Caucasians. The difference in physical activity was not explained by disparities in income, marital status, or disability status.
Physical activity levels, measured by International Physical Activity Questionnaire (IPAQ) and Godin Leisure-Time Exercise Questionnaire (GLTEQ), were significantly associated with confidence, expected benefits, goal setting and planning strategies, and functional limitations for physical activity among African-Americans living with MS (Figures 2 and 3).

CONCLUSION

This study suggests that African-Americans living with MS are engaging in lower levels of physical activity than Caucasians. Self-efficacy, expected benefits, functional limitations as impediments, and goal setting and planning were identified as correlates of physical activity in African-Americans with MS. These variables may be important targets of promoting physical activity in this population. Such observations are important considering that there are successful behavioral programs for changing these variables and promoting physical activity in samples of persons with MS who are mostly Caucasians. Such interventions could readily be adapted for African-Americans, and could consider socio-demographic and cultural differences between African-Americans and Caucasians.

FUTURE RESEARCH

Ms. Kinnett-Hopkins will use these results for developing a physical activity intervention grounded in SCT theory and guided by input from African-Americans living with MS. This future study will be conducted with the hope of developing an intervention that increases physical activity levels in African-Americans living with MS. The ultimate goal would be for optimizing symptom, and perhaps disease, management through physical activity in this MS population.

References:
In “Feature Focus” this issue (page 4), NARCOMS Now spoke with neurologists about pediatric MS. While participants must be at least 18 years of age to join NARCOMS, participants are asked about their age at MS diagnosis when they enroll.

**Age at Diagnosis**

The majority of NARCOMS participants report being diagnosed between the ages of 20 and 50 years of age, with an average age of 37.8 years of age. This is similar to the MS population as a whole. On average in NARCOMS, males are diagnosed at a slightly older age (38.7) compared to females (37.5).

Some NARCOMS participants report a young age of diagnosis; in fact, 1.5% of participants report a diagnosis age that would qualify as pediatric MS. More females (1.7%) compared to males (1.1%) report an MS diagnosis before age 19. Of those diagnosed before age 19, the average age of diagnosis reported was 16.7 years.
Initial Symptoms by Age of Diagnosis

In addition to age of diagnosis, participants are also asked about their first symptoms. Visual difficulties, such as vision loss or double vision, numbness or weakness in limbs, and balance and walking issues, are the most common first symptoms in those diagnosed at both younger and older ages. The proportion reporting each type of first symptoms is similar with the exception of vision loss, where a higher percentage of those with a younger diagnosis age reporting vision loss as a first symptom (61.3%), compared to older age of diagnosis (41.6%).

Recovery from First Symptoms

Most NARCOMS participants report they fully recovered from their initial MS symptoms, regardless of the type of symptom.

Overall a higher proportion of those with a younger diagnosis (74.5%) recovered from their first symptoms, compared to those who were diagnosed as an adult (61.9%).
Results Released from Positive Phase III Clinical Trial of Ocrelizumab in Primary Progressive MS

For the first time, a treatment has shown efficacy in reducing clinical progression in participants with Primary Progressive Multiple Sclerosis (PPMS). Results of a ORATORIO, a Phase III clinical trial of the investigational medicine ocrelizumab (Genentech/Roche) showed treatment of those with PPMS significantly reduced the progression of clinical disability sustained for at least 12 weeks compared with placebo, as measured by the Expanded Disability Status Scale (EDSS).

ORATORIO was a double-blind, global multi-center study evaluating the efficacy and safety of ocrelizumab (600 mg administered by intravenous infusion every six months; given as two 300 mg infusions two weeks apart) compared with placebo in 732 people with PPMS. The primary endpoint of the ORATORIO study was time to onset of confirmed disability progression (CDP), defined as an increase in EDSS that lasts for at least 12 weeks.

Xavier Montalban, MD, PhD, president of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) executive committee and chair of the Scientific Steering Committee of the ORATORIO study, presented the results at the 31st congress of ECTRIMS on October 10, in Barcelona, Spain. (Abstract 228 | tinyurl.com/h44o848)

Overall, the frequency of side effects associated with ocrelizumab was similar to placebo; the most common side events were mild-to-moderate infusion-related reactions (side effects from having an IV). The frequency of serious adverse events associated with ocrelizumab, including severe infections, was also similar to placebo.

“People with the primary progressive form of MS typically experience symptoms that continuously worsen after the onset of their disease, and there are no approved treatments for this debilitating condition,” said Sandra Horning, MD, Roche’s Chief Medical Officer and Head of Global Product Development. “Ocrelizumab is the first investigational medicine to show a clinically meaningful and statistically significant effect on the progression of disease in primary progressive MS.”

In addition to ORATORIO, the Phase III clinical development program for ocrelizumab includes OPERA I and OPERA II, which are randomized, double-blind, double-dummy (all participants take two injections, one active and one placebo), global multi-center studies in people with relapsing forms of MS. (Abstract 190 | tinyurl.com/jchf4u4) The studies showed that compared with the interferon β-1a Rebif (EMD Serono/Pfizer), treatment with ocrelizumab significantly reduced the annualized relapse rate, the progression of clinical disability, and the number of lesions in the brain on MRI.

Genentech says it plans to pursue marketing authorization for ocrelizumab in relapsing MS and in PPMS. Data from the OPERA I and II studies and from the ORATORIO study will be submitted to the U.S. Food and Drug Administration in early 2016.

ALSO @ ECTRIMS...

Could Taking Minocycline at CIS Reduce Risk of Developing MS?

Dr. Luanne Metz, University of Calgary, reported the findings of a Phase III trial of a relatively inexpensive oral antibiotic called minocycline, often prescribed to treat acne.
In addition to its bacteria-killing action, it reduces inflammation. The trial tested minocycline against placebo in 144 people who had a clinically isolated syndrome. Results showed that over six months, those taking twice daily minocycline had a 44.6% reduced risk of developing definite MS, compared to those taking placebo. Additionally, no unexpected side effects occurred. This antibiotic does carry several warnings, however, including advice against taking it while pregnant. (Abstract 227 | tinyurl.com/pqtu4nx)

**Lemtrada 5-Year Results Continue to Show Effectiveness**

Reports from two ongoing long-term studies of alemtuzumab (Lemtrada,® Genzyme, a Sanofi company), approved for relapsing MS, suggest this therapy continued to show effectiveness against relapses and brain volume loss after five years in people who had participated in the CARE 1 and CARE 2 trials. May of these individuals received only two short courses of treatment, a year apart. Side events (that have been well documented in the medication guide | tinyurl.com/oa9ptpb) were comparable or reduced during the extension period compared with the original studies. (Abstracts 151, 152 | tinyurl.com/nc8m9bg / tinyurl.com/plkxd6od)

**Additional Anti-LINGO Results Positive for Optic Neuritis**

In April 2015, drug maker Biogen reported promising results from a phase 2 clinical trial of the myelin repair strategy called anti-LINGO. The study involved IV infusions or placebo every 4 weeks for 20 weeks, to 82 people who had a first episode of optic neuritis. Individuals who were given anti-LINGO had faster nerve signals along the optic nerve of the affected eye, compared to those on placebo. At ECTRIMS, Biogen researchers reported that in a sub-study involving 39 participants, those on anti-LINGO also had reduced loss of nerve signal strength in the unaffected eye, compared to placebo. The treatment was well-tolerated except for some reactions related to receiving an IV. Another phase 2 trial is ongoing in people with relapsing MS. (Abstract 231 | tinyurl.com/p3pon5s)

**Thyroid-Like Hormone for Repair?**

Dr. Dennis Bourdette, a researcher from Oregon Health and Science University, reported that he accelerated myelin repair in mice using an experimental drug called sobetirome. It is a thyroid-like hormone currently in clinical trials for lowering cholesterol. It is widely known that the thyroid hormone boosts the capabilities of myelin-making cells, but is not viable to treat MS because of adverse effects on heart, bone, and muscle. Sorbetirome may work without these side effects. The National MS Society is funding this team to explore this option in MS models. Demonstrating safety and effectiveness in MS may take less time than usual, since it is already in clinical trials for another indication. (Abstract P583 | tinyurl.com/p93n57t)

**High-Fat, High Protein Diet Protective in MS Patients?**

MS researchers are exploring intermittent fasting as a way to fight inflammation. In addition, one group of German researchers conducted a small trial (48 participants) with relapsing-remitting MS studying various diets that may affect “ketone bodies.” These are molecules in the liver that may protect the brain and spinal cord. Dr. Markus Bock and colleagues (Universitätsmedizin Berlin) compared participants who followed their usual diets to participants who followed either the ketogenic diet (high-fat, high protein, low carb) or a prolonged fasting diet (7-day fast followed by a Mediterranean diet). Both groups on the diets reported improved quality of life and had improved cholesterol levels. The researchers say larger studies are needed to fully explore the potential benefits of these approaches. (Abstract P1509 | tinyurl.com/ptt5ho4)
Clinical Trials in MS

**Nationwide Phase I Study to Determine Safety of Experimental Antibody in Treating Relapse (October 2015)**

**Summary:** Investigators nationwide are recruiting 30 people with MS for a phase I study to determine the safety and tolerability of rHIgM22, an experimental antibody. Participants may remain on their current therapy throughout the study. The study is enrolling participants experiencing a clinical acute relapse (new or worsening neurological symptoms attributable to MS preceded by a stable or improving neurological state of at least 30 days) and with at least one new, active lesion (damaged area) on MRI scans.

**Sponsor:** Acorda Therapeutics, Inc.

**Rationale:** Although the body repairs some damage to nerve-insulating myelin that occurs in MS, this repair is insufficient. One strategy under study is to stimulate the body’s own internal repair capabilities. With funding from the Hilton Foundation, NIH, the National MS Society and others, Moses Rodriguez, MD, and colleagues (Mayo Clinic Foundation) identified a human antibody—rHIgM22—that targets and attaches to myelin-making cells. When given to mice with an experimental MS-like disease, rHIgM22 promotes myelin repair. This antibody was well tolerated in another phase I study (trial NCT01803867, as listed on clinicaltrials.gov) in 55 people with all types of MS. ([Abstract #P4.339](https://tinyurl.com/olkzzyv) Annual Meeting of the American Academy of Neurology 2015)

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**How does Ocrelizumab work?**

Ocrelizumab is an injectable humanized monoclonal antibody designed to selectively target CD20-positive B cells. What does all of that mean? First some definitions:

**Antibody:** A protein found in our bodies that is used by our immune system to identify and neutralize things that attack our immune system

**Humanized antibody:** These are non-human antibodies that have been modified to be recognized and accepted by our bodies

**Monoclonal antibody:** These are antibodies that are made from a specific type of cell that will attach to a specific location in the human body

**CD20 positive B Cells:** A type of immune cell thought to play a key role in preserving myelin, the nerve cell insulation

So saying, “Ocrelizumab is an injectable humanized monoclonal antibody designed to selectively target CD20-positive B cells” means that Ocrelizumab binds to CD20 proteins on B cells, possibly preserving important functions of the immune system.
**Eligibility:** Men and women between the ages of 18 and 70 with a diagnosis of MS are eligible. The study is enrolling participants with a clinical acute relapse; an MRI will be performed to confirm that there is an active lesion (damaged area). There are detailed exclusion criteria related to laboratory, cardiac, immune and other factors.

Participants will remain on their current therapy throughout the study. Upon entering the study with an acute relapse, subjects will receive high-dose oral steroids for five days, a standard treatment for an acute relapse. Following completion of the oral steroids for the acute relapse the subjects will receive either a single dose of rHlgM22 or placebo.

Investigators are testing 2 dose levels. For each dose, 10 participants are being randomly assigned to receive active treatment (rHlgM22) and 5 are being randomly assigned to receive inactive placebo, both via a single intravenous infusion. Blood samples will be collected from participants before and at specified times for up to 48 hours after dosing, so participants must agree to remain in the hospital for that time. Participants are being followed for 180 days after dosing, which includes return visits to the clinic and MRI scans.

The primary outcome of the study is to determine the safety and tolerability of rHlgM22 in people with MS. Adverse events are being monitored throughout the study. The investigators will also evaluate how this experimental treatment is absorbed in the body, and how the immune and nervous systems react to it. Phase I studies are the first of three stages of clinical trials that determine whether an exploratory treatment is safe and beneficial.

**Contact:** Kevin Cronin, Manager Corporate Communications, kcronin@acorda.com, 914-326-5279, or visit the trial’s listing on clinicaltrials.gov to find the site nearest you.

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**Randomized Controlled Trial of Vitamin D Supplementation in Multiple Sclerosis**

**Summary:** This is a multicenter trial in which participants with relapsing-remitting MS will be receive high-dose or low-dose vitamin D for two years. All participants will be given glatiramer acetate (Copaxone) for free during the study. The purpose of the study is to assess if vitamin D is effective in reducing relapses and new MRI lesions in people with multiple sclerosis.

**Rationale:** This trial is being done because previous studies of vitamin D levels in people with MS show that those with lower vitamin D levels are more likely to have MS attacks and new MS lesions develop on brain MRI, but it is not known if giving vitamin D supplements reduces the amount of MS activity.

**Sponsor:** Johns Hopkins University

**Eligibility and Details:** To be eligible, participants must have relapsing-remitting MS, a certain number of relapses and new MRI lesions in the past one to two years. They must have no limitations in walking because of the MS. Participants must be aged 18 to 50. They must not have received Copaxone for more than 3 months in the past. They must not have been on natalizumab (Tysabri), fingolimod (Gilenya), or fumarate in the past six months and cannot have received any other unapproved MS therapy or chemotherapy. Participants must not have taken more than 1,000 IU/day of vitamin D3 in the three months before the first study visit. Those with certain other health conditions or taking certain medications will be excluded for the sake of safety.

**Contact:** vitamindtrialms@jhmi.edu

For a comprehensive list of clinical trials in the United States, visit the National Institutes of Health’s website, www.clinicaltrials.gov. It can be searched by topic, by location, or even search for a phrase.
Find the following hidden words:

wreath, stockings, candles, holly, gifts, bells, garland, evergreen, sweets, snowman, mistletoe, caroling, gingerbread, candycane, dreidel, tree

FIND THE ANSWERS TO THIS WORD PUZZLE ONLINE:
www.narcoms.org/narcomsnow/play/answers
“Moving Forward, Not Looking Back!”

I was diagnosed with Primary Progressive MS 18 years ago, at age 53. I was grateful that I had already had so many good life experiences, such as cross-country skiing, jogging, and climbing the La Luz Trail in the Sandia Mountains in Albuquerque, New Mexico.

For several years, I tried many therapies, including injections, infusions, and oral therapies, many with short-lived success. When I discontinued them, I no longer had fatigue.

In the meantime I got on with my life! I taught a water exercise class, moderated a support group meeting, and offered yoga classes by way of a grant provided by one of the pharmaceutical companies.

Additionally I began an adaptive ski program, joined a wheelchair basketball team, took up sled hockey, and, to celebrate my 70th birthday, went paragliding. I have participated in fundraising activities and volunteered several summers at a camp for children in wheelchairs.

Overall, I feel I have been afforded an active, enjoyable life. I’m not wasting time whining about what I can’t do. Instead, I expend my efforts on finding ways to do as many enjoyable things as I am able.

—Patricia M.

Not all medications will work the same for everyone. Please consult your physician about how to treat your symptoms.

Did you know? Now, in addition to emailing us at narcomsnow@narcoms.org, you can complete a submission to “Faces to NARCOMS” using our online form. Check it out: www.narcoms.org/narcomsnow/faces-of-narcoms