MACS/WIHS COMBINED

Spring 2023

CELEBRATION 07

MWCCS Newsletter

WELCOME BACK! V103 IS HERE!

The MACS/WIHS Combined Cohort Study (MWCCS) Spring newsletter is here welcoming visit 103 and celebrating 30 years of longitudinal clinical research. We are excited for what 2023 has in store as we happily embrace our new normal, cautiously, two years after the start of the pandemic. The MWCCS team is excited to see everyone in person, sharing stories, eating, laughing and mostly making important contributions to clinical research that continues to help change lives.

You'll be hearing more about how the MWCCS team will acknowledge this historical milestone later this year during your visits. In the meantime, take a look at what's new in this issue, the studies returning for V103, articles on seasonal depression, how to avoid weight gain, how to refer someone to the study and a spotlight article on our very own Darlene Johnson.

WHAT'S NEW? PHONE 1st!

We've heard your feedback! The MWCCS team strives to make your visits more

convenient and flexible. We now offer the option of completing your main interview by phone, before your in person visit. If you chose to do a phone interview, the main visit can be shortened in person by up to 1 hour! An MWCCS RA will be available every Friday to conduct interviews. Requirements for phone visits are:

- Participants will have to call in to the office during the hours of 9am and noon
- Participants must be able to complete a full interview at the time of the phone call
- Visit 103 has to be completed within 2-6 weeks of the phone interview
- Contact Pam at 312-810-5746 or Ruby at 312-825-2557 to get started



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WHAT'S NEW? A SLEEP STUDY!

Are you getting enough sleep? Lack of quality sleep is suspected to negatively affect health conditions, such as hypertension, type 2 diabetes and stroke among others. It's possible that women are more susceptible to poor sleep-related outcomes than men.

A new sub-study will look at the role sleep plays in the health of women participants. The study will also track how the sleep quality in men differs from women.

This exciting new sub-study will include 40 women who participated in the iDoze study that ran from 2018

to 2021. Overnight sleep monitoring will be completed at home. A high-tech Nox A1 sleep monitor and watch-like

Actiwatch Spectrum Plus will record eye movements, electroencephalogram (EEG), electrocardiogram (ECG),

breathing, oxygen saturation, respiratory efforts and leg movements. The assessment lasts for one week. Partici-

pants will receive a modest compensation for their participation in this study.

WHAT'S BACK FOR V103?

The MWCCS study is back for visit 103 in 2023. And several intriguing sub-studies are returning for V103

Echocardiogram (ECHO)

ECHOs are pictures of your heart's chamber -- valves, walls and blood vessels (aorta, arteries, veins) – created by soundwaves using an ultrasound. The ECHOs will be completed off site at Cook County Hospital in the early evenings

Pulmonary Function Testing (PFT)

A PFT uses a spirometry to test lung function. The test is performed by breathing into the spirometer mouth piece before and after taking a bronchodilator. PFTs produce a lung function report that is sent to a pulmonologist. If interested, the PFT takes place the same day as your core visit.

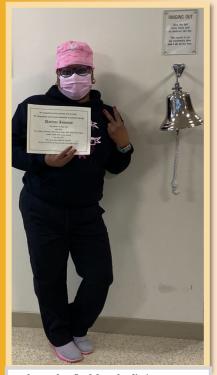
Neuropsychological Assessment (Brace & Brace+)

The Brace and Brace+ battery of questions assesses mental functions to see how well your brain is working. The computer tablet administered exam tests intellect, attention, learning, memory, visuospatial skills and problem-solving. The Brace and Brace+ studies are conducted during core visits.

These and other exciting opportunities are available for V103.

DID YOU KNOW?





Darlene at her final day of radiation treatment

SPOTLIGHT IN COURAGE: DARLENE JOHNSON

If you haven't seen Darlene Johnson in a while, there's something you'll probably notice about the longtime Research Assistant right away. It might be a close-fitting cap. Or it could be a colorful pink scarf. What you won't see are her signature locs. Darlene recognizes that, for more than 20+ years, the women in the study have shared the most private details of their lives with her. Now it is her turn, and she wants to be very candid with everyone.

"I had Triple Negative Breast Cancer, stage 2B. It's highly aggressive. It made my hair fall out quicker. I lost my eyebrows, my eyelashes. I'm an open book when it comes to this diagnosis. I'd rather people to know than not know. I'm willing to share with anyone."

According to the Centers for Disease Control and Prevention, breast cancer is the second most common cancer in women in the United States. About one in eight women will get breast cancer during her life. One in five Black women with breast cancer have triple negative breast cancer, more than any other group. Triple negative breast cancer, the kind that Darlene had, grows quickly and has fewer treatment options than any other type of invasive cancer, according to the American Cancer Society.

Darlene is speaking out so that other participants know she's been where they are. She credits the two-tiered support from her family and doctors to help her fight back against cancer.

"Supportive. My family has been very supportive because my sister is a three-time survivor. She had it in the left breast I had it in the right. So we've gone through this before. I would advise you to go with your gut on your treatment plan. I didn't second guess my plan because I had a great team of doctors. It turned out absolutely wonderful." As Johns Hopkins online notes, some breast cancers can be genetic, which means the cancer gene can be inherited. Given her family history, Darlene had valid concerns.

"I immediately wanted to do a double mastectomy. But they did genetic testing and determined that my cancer wasn't genetic. So my daughter was safe and my son was safe. And the chemo (chemotherapy) did the job and shrank the tumor. I still had to have a lumpectomy. I had to finish the radiation. But on October 26th, they couldn't find the cancer. I was cancer free!"

A breast self-exam for awareness, such as the kind recommended by the Mayo Clinic, is an exam of your breast that you do on your own to determine if there are any changes. Darlene learned about her illness by chance but would like others to be more proactive.

"I wasn't doing self-exams, I was in the shower and I felt something. I would definitely suggest selfbreast exams. I'm just grateful I caught it in time. And I want everyone to do self-breast exams! I'm willing to show anyone how to do them." As for her new look, Darlene admits to being a little peeved about some of the reactions she's gotten. "I hate when people stare and assume things. I'd rather people just come out and ask me. When you see a woman with a bald head, never assume she cut it. She might have health problems. At first, I was self-conscious about my bald head. I didn't want to go out without a hat. When I looked in the mirror, I didn't see myself because I had no hair. And if you don't know what to say, just don't say anything."

Ultimately, Darlene prefers to have frank exchanges about her illness and recovery. "I don't mind sharing my story. I was offered therapy but I chose not to go. When I tell my story, that's my therapy. I'm still on my journey. I'm still learning."

Links to learn more are listed below:

https://www.cancer.org/cancer/breast-cancer/about/types-of-breast-cancer/triple-negative.html

https://www.cdc.gov/cancer/breast/basic_info/

https://www.mayoclinic.org/tests-procedures/breast-exam/about/pac-20393237

https://www.hopkinsmedicine.org/health/conditions-and-diseases/breast-cancer/hereditary-breast-cancer

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DON'T FALL BACK! FIGHTING SEASONAL DEPRESSION

Do the short days and cloudy skies of winter make you feel out of sorts? Feeling down when it's time to turn back the clocks may have made you sad. Not just traditional sadness, but something called SAD, or seasonal affective disorder, that commonly affects people in the late fall and early winter and goes away during the spring and summer.

In addition to typical depression symptoms, such as having low energy, feeling hopeless or worthless, and feeling sluggish or agitated, SAD sufferers may have specific symptoms. They include:

Oversleeping (hypersomnia)

Overeating, particularly with a craving for carbohydrates Weight gain

Social withdrawal (feeling like hibernating)

SAD is more likely to affect women than men and is more common in northern climates, like Chicago, where there are shorter daylight hours in the winter. While the causes of SAD are not fully known, studies suggest that sufferers have lower levels of a brain chemical called serotonin, which regulates mood. Sunlight may help to keep serotonin levels normal.

So, what can those with SAD do during the long winter to feel better?

Light Therapy

Sitting in front of a bright light box (10,000 lux) 30-45 minutes first thing in the morning has shown to help some SAD sufferers. Light therapy lamps are easy to find at your local retailer or online for a minimal cost. However, if buying a therapy lamp is not an option, open the blinds and shades as much as possible on sunnier days.

Therapy

Cognitive behavioral therapy for SAD (CBT-SAD) can help people learn to cope. It typically involves weekly group ses sions focusing on replacing negative thoughts about winter time with more positive ones. If you cannot make therapy sessions, a helpful technique to remember is to reframe your thoughts around winter. Remind yourself that winter is only temporary and warmer weather and longer days will return. Making future plans for the warm weather may encourage positive thoughts during this time as well.

Vitamin D

People with SAD often have vitamin D deficiency, the vitamin that your body uses for normal bone development and maintenance, due to lack of sun exposure. Talking to your provider about checking your vitamin D levels may help improve your mood.

Medication

SAD is a form of depression and some SAD patients benefit from a prescription of antidepressants known as selective serotonin reuptake inhibitors (SSRIs).

Talking to your provider about the symptoms listed above or any significant changes in your mood during this time is key to getting ahead of seasonal affective disorder.



LOSE TO WIN! HOW TO COMBAT WINTER WEIGHT GAIN



Have you put on a few pounds lately? The rich foods and leisurely pace of the winter months often leads to weight gain. If you're not careful, the temporary pounds can become permanent.

According to the Centers for Disease Control and Prevention, even a modest weight loss of 5% to 10% your total body weight is likely to produce positive health outcomes, such as improved blood pressure, blood cholesterol and blood sugars. The CDC recommends gradual and steady weight loss, about 1 to 2 pounds a week, as the best method for keeping the weight off. But how do you get started? Here are a few tips to begin your weight loss journey.

Log in - Keeping a log of everything you eat and drink, and when, can help you discover patterns. You might, for example, reach for the chips while you're watching TV. There are smart phone apps that can help you keep track of what you're eating.

Home in on Habits – Do you eat when you're not hungry? Skip breakfast? Eat standing up? Recognizing an un healthy habit is the first step toward doing better.

Level Up - Once you've identified an unhealthy habit, you want to replace it with a healthy one. Do you gorge on midnight snacks? Try closing the kitchen after the dinner hour.

Lean in, be patient and give yourself grace throughout. Practice your healthy new habits but don't be discouraged if you fall short on occasion. Remember, this is not just about losing weight but a lifestyle change. Gradual steps lead to lasting results!

IS IT A COLD OR FLU OR COVID?

Wintertime in Chicago is a peak season for colds, the flu and Covid-19. But with so many overlapping symptoms it's difficult to know if you'll need cough syrup or a Covid test. This handy chart from the National Institute on Aging shows common signs of

all three illnesses

You may only have some of these symptoms and they may be more or less severe. Bottom line, if you feel sick stay home, call your doctor, and ask if you need to get tested.

	Common Symptoms*	Cold	Flu	COVID-19
Common Symptoms of a Cold, the Flu, and COVID-19	Fever and/or chills		\bigotimes	\bigotimes
	Headache		\bigotimes	\bigotimes
	Muscle pain or body aches		\bigotimes	\bigotimes
	Feeling tired or weak		\bigotimes	\bigotimes
	Sore throat	${ \ \ }$	\bigotimes	\bigotimes
	Runny or stuffy nose	\bigotimes	\bigotimes	\bigotimes
Learn more at www.nia.nih.gov/flu	Sneezing	\odot		
www.ma.mi.gov/mu	Cough	\bigotimes	\bigotimes	\bigotimes
NIH National Institute on Aging	Shortness of breath or difficulty breathing		\bigotimes	\bigotimes
*Symptoms may vary based on new COVID-19 variants and vaccination status.	Vomiting and diarrhea		\bigotimes	\bigotimes
	Change in or loss of taste or smell			\bigotimes



(Retrieved from the NIH)

MWCCS NEW STAFF HIGHLIGHTS

MEET RUBY HERNANDEZ



Ruby is a Registered Medical Assistant, Emergency Room Clinician – and a bundle of energy. She chose to come to the MACS/WIHS Combined Cohort Study for a couple of reasons. "I wanted to take a look at some-thing new." Ruby also needs research experience to complete her master's degree in Forensic Anthropology. "I love Anthropology. Anthropology is the study of humans. And this is a very human study." In addition to MWCCS, Ruby works for Advent Health of La Grange, Illinois and Gulfport Memorial Hospital in Gulfport, Mississippi. If you wonder how the mother of two finds the time she'll just smile and insist she likes to

stay busy. Ruby is quick to say what she likes best about working for the MWCCS. "The participants! Everyone has a story."

REFER A FRIEND

Do you know someone interested in participating in the MWCCS study? We can use your help enrolling women. You will receive a modest compensation for each referral that meets the criteria.

Who is eligible? To qualify for the study, women must be between the ages of 30 – 70. To learn about all eligibility requirements please call.

The MWCCS is a long-term study with at least one visit per year. The visits include:

- Interview and Questionnaires
- •Mental health assessment and cognitive and physical function assessment
- Vitals and body measurements
- Gyno exam with pap smear
- Collection of blood, urine and other specimens

Additional tests will assess the health of the liver, heart and lung organs over the course of the study. Modest compensation will be provided for each visit.

Those interested can call (312) 810-6091 or (312) 810-5746.

