

## Johnston County Osteoarthritis Project (JoCoOA) Update

Dear Friends:

I don't know what amazes me more; the fact that another year has gone by, or the fact that each year we continue to gather so much vital new information that is advancing our understanding of osteoarthritis and other chronic conditions like diabetes and heart disease.



*Joanne Jordan, MD, MPH*

We're also gearing up to kick off several important new local studies this year. In other good news, the Johnston County Osteoarthritis Project has received renewed funding from the Centers for Disease Control and Prevention for the next five years.

*(Continued on next page...)*

### Holiday Open Houses are back in 2016!



Come celebrate the holidays with us! We will be hosting two Open Houses at Noble Plaza, Building G (Research Clinic). Join us for fellowship and light refreshments. Please call us at 919-934-1295 by Friday, December 9th to let us know which day you can come and if you will be joining us in the morning or the afternoon. We are looking forward to seeing you!

Tuesday, December 13th from 10:00 am - Noon; and 1:00 pm - 3:00 pm

Thursday, December 15th from 10:00 am - Noon; and 1:00 pm - 3:00 pm

Your involvement plays a critical role in advancing medical research, which is helping scientists and doctors find new ways to improve the lives of those living with diseases such as osteoarthritis. Rest assured that your efforts are truly making a difference!

When you are contacted in the near future by a member of our team, we hope you will choose to continue participating in the Johnston County Osteoarthritis Project (*JoCoOA*) -- one of the few community studies of its kind anywhere in the world.

**In this issue of our newsletter, you will hear exciting updates and learn about new plans such as:**

- Enrollment of **NEW** eligible participants into *JoCoOA* in 2017, including adding younger people starting at age 35.
- A new study enrolling locally, called “**WE-CAN**” or “**Weight Loss and Exercise for Communities with Arthritis in North Carolina**,” to show how weight loss and exercise programs can be effective in real-world community settings like ours to help improve pain and stiffness of knee osteoarthritis.
- Important new research to look at how the things we eat may affect osteoarthritis. It will be led by Dr. Richard Loeser, one of the foremost arthritis researchers in the US and a member of our UNC Thurston Arthritis Research Center. We are proud to have him join our *JoCoOA* team.
- A new study called **PhysicAI Therapy vs. INternet-based Exercise Training for Patients with Knee Osteoarthritis (PATH-IN)**. This study is evaluating a newly developed internet-based exercise program for people with knee osteoarthritis (OA).
- Information about a new allergy, “alpha-gal” meat allergy, which can occur after tick bites. One of our own staff provides a first-hand view of this puzzling condition.

The work we do would not be possible without your dedication and participation in essential research being conducted every day. We are most grateful to have you as part of our team! We look forward to seeing you soon at our upcoming Open Houses and wish you and your families good health in the year ahead.

# Important New Research Being Conducted In Johnston County

## The “WE-CAN” study



*Study coordinators attend community events to encourage enrollment in new trials such as WE-CAN.*

An exciting new study is underway in Johnston County called **Weight loss and Exercise for Communities with Arthritis in North Carolina, or WE-CAN**. As the name implies, this study focuses on empowering adults with knee osteoarthritis to lose weight through diet and exercise. The UNC Thurston Arthritis Research Center and Wake Forest University are leading this research with locations in Johnston, Forsythe and Haywood counties. This type of exercise and weight loss study has already been proven to help with pain and stiffness in osteoarthritis in a university study, and now for the first time, it will be tested to see how well it can work in real-world, community settings such as ours. The program will be conducted at a research study office in the north end of the Medical Mall in Smithfield, and in the Community Center in Clayton. To be eligible for the study, people must have knee pain, be over age 50, and be overweight. For more information, contact us by phone at: 919-989-8005; or email us at: [wecan@unc.edu](mailto:wecan@unc.edu).

# The “PATH-IN” study

Kelli Allen, PhD, and her team at the UNC Thurston Arthritis Research Center are currently conducting a study called **PhysicAI Therapy vs. IN**ternet-based Exercise Training for Patients with Knee Osteoarthritis (PATH-IN). This study is evaluating a newly developed internet-based exercise program for people with knee osteoarthritis. The PATH-IN study is based at the Thurston Arthritis Research Center at The University of North Carolina at Chapel Hill, with collaborators at Duke University Medical Center, and is funded by the Patient Centered Outcomes Research Institute. PATH-IN participants are randomly placed into one of three groups. One group receives standard physical therapy, one group receives access to the internet-based exercise training program, and one group is a “waiting list” control group that receives access to the treatments at the end of study participation. The study examines the effectiveness of each intervention for improving pain and functional outcomes at 4 month and 12 month assessment visits. The study will also assess whether the internet-based exercise training program is as effective as physical therapy, a guideline-recommended component of care for knee osteoarthritis. If the internet-based exercise training program is found to be as helpful for knee OA, this would be another treatment option for patients who may not have access to or be able to afford physical therapy. This study will also determine whether the internet-based exercise program is more effective for patients who have certain characteristics (e.g., milder joint disease).

## The Role of the Microbiome in Osteoarthritis

The UNC Thurston Arthritis Research Center’s Director of Basic and Translational Research, Dr. Richard F. Loeser, Jr., has received an Arthritis Foundation award to study the role of the gut microbiome in osteoarthritis. The gut microbiome refers to the bacteria that normally live in a person’s intestine. This study will see if the kinds of bacteria in people with osteoarthritis are different from the bacteria in people who do not have osteoarthritis. Diet and probiotics, such as yogurt and Acidophilus milk, are factors that can affect the gut microbiome. This will be one of the first studies to look at how the microbiome and osteoarthritis might be related. Eligible people in *JoCoOA* who have agreed to be contacted about future studies will be asked if they would like to be a part of this additional study.

# What is alpha-gal? An interview with JoCoOA staff member Lynn Joyner

Lynn Joyner has been with JoCoOA as a research study interviewer and clinic examiner for 15 years. She has been diagnosed with alpha-gal meat allergy and volunteered to share her story with our readers.



Lynn Joyner

## What is alpha-gal and how does a person get alpha-gal?

Alpha-gal is a food allergy that some people develop, possibly as a result of being bitten by a Lone Star tick.

People with this allergy may have serious reactions after eating food made from mammals. Mammals are animals that have live-birth offspring like cows, pigs, and deer, but not chickens. People who have alpha-gal allergy react to beef, pork, lamb and venison. Reactions can include hives, swelling, difficulty breathing, and shock.

## How long did you have alpha-gal before you were diagnosed, and how were you diagnosed?

I had been dealing with this condition for nine months with no clue as to what was causing my reactions. After talking to someone who had alpha-gal, I realized that my multiple trips to the emergency room for allergic reactions were likely the result of this allergy. I had a history of tick bites so I made an appointment with a doctor who specializes in allergies and was diagnosed. I was fortunate that it only took nine months to figure it out. Some people have gone 10 or more years without knowing what was causing their problems. The allergy is difficult to diagnose because most food allergies, such as peanut allergy, occur immediately after eating a food. Alpha-gal allergy reactions can take as long as four to eight hours between the time that a person eats these foods and has a reaction, so they may not make the connection.

## What were your symptoms?

I started with hives on my hands, lower arms and feet. As I continued to eat meat, the reactions became more frequent and more severe. I made five trips to the emergency room for anaphylactic shock, which is a severe allergic reaction that can be fatal if not treated right away.

## How has alpha-gal affected your life and how have you adapted?

For me, alpha-gal has definitely been life-changing. Besides no longer being able to eat meat from mammals, I have had to stop using anything with mammal by-products. Many foods use products from mammals as preservatives. In addition, a lot of what we use in everyday life has some form of ingredient from mammals. For example, shampoos, lotions, and toothpaste can all have contents from mammals. Often prescription and over-the-counter drugs have some sort of mammal by-product in them. I am so sensitive that I can no longer wear any leather shoes or clothes made out of wool. One of my trips to the hospital was from just smelling fumes from meat being cooked. I now read every label before I buy anything, and I am very limited in being able to eat out. I should point out that many people who have this allergy do not react as strongly, or to as many things as I do.

## How do I know if I have this allergy, and if I think I might, what should I do?

If you experience any of the symptoms I've mentioned, or if you have unexplained hives or swelling around your lips and face, you need to visit your doctor and ask about the blood test used to determine if you have alpha-gal.

## Is alpha-gal considered rare?

We do not know how common alpha-gal food allergy is, but it is suspected that a large number of people are undiagnosed. Researchers are trying to learn more about alpha-gal through ongoing studies. The *JoCoOA* project, for example, will include a questionnaire on allergies in its next data collection and will keep a portion of the blood samples taken in order to further study this allergy.

*IMPORTANT: These samples will not be used to diagnose the condition for study participants. If you think you may have an allergy, talk to your doctor or other health care provider.*