Medical Xpress

Listening to lupus

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Dr. Lenore Buckley (third from left) of the Lupus Program with Jacinta Renaldi, Jiha Lee, and Sushmitha Fernandes. Credit: Robert Lisak

Lupus is a mysterious chronic illness that primarily affects women in their prime of life. In people with lupus, the immune system goes awry, attacking healthy tissue. While there is no cure, there are many options for treatment, including ones being studied at Yale School of Medicine. For May, lupus awareness month, YaleNews spoke to Dr. Lenore Buckley, professor of medicine in the Section of Rheumatology, who

recently launched an innovative clinical program for patients with lupus. Following is an edited version of the conversation.

When did the clinical lupus program at Yale start, and what does it entail?

About a year and a half ago we decided to start a dedicated program for the care of people with lupus. Lupus is a multisystem inflammatory disease that affects the joints, but it can also affect the lungs, skin, heart, and other organs. It requires interdisciplinary care so we set up special outpatient clinical programs at Yale-New Haven Hospital (YNHHS) outpatient sites in North Haven and on the St. Raphael's campus.

One of the challenges of lupus is that it's a multisystem disease that can affect young people. In fact, the younger you are, the more severe it can be. It predominantly impacts women, especially women of color. And many people who are impacted by lupus have challenges to accessing care. Getting to the doctor, getting medication, and staying on medication is difficult partly because many patients are young and partly because of barriers of transportation and coordination of care. Because of that, we felt that the care should not only be multidisciplinary but that the patient needed to be the focus of care.

What is unique about Yale's Lupus Program?

The program was built upon the strong pre-existing and ongoing care of lupus patients at Yale, provided over many years by Drs. Cristina Brunet, Janine Evans, Liana Fraenkel, Insoo Kang, and Gordon Hutchinson and their colleagues in the Section of Rheumatology. To enhance our patient-centered approach, we developed a Wellness Program, led by Jacinta Rendali, a rheumatology nurse practitioner. After working individually with patients to understand their goals, barriers to care, and knowledge

about their disease, Jacinta sees patients quarterly to help them understand their disease and treatments, participate in decision making, and understand how to navigate the health care system to optimize their care, including how to access care during disease flare-ups to decrease hospitalizations.

You said that the majority of those impacted are women?

Yes. These are many aspects of lupus care that involve women's health and so there are modules in the Wellness Program about careful planning of pregnancies and follow up during pregnancy and regular preventive care, including immunizations, Pap smears, mammograms, and assessment of bone health as women age.

People with lupus also need to practice sun avoidance because sun exposure can make symptoms worse. They are at higher risk for cardiovascular disease and strokes, so the programs includes modules about sun protection and cardiovascular health including exercise, healthy eating, monitoring weight, and cholesterol and blood pressure screening.

And it's a chronic disease, correct?

Yes, though remissions can occur. Because it is chronic, an important focus is maintaining good health as people age. We developed the wellness program because we felt that doctors often didn't have the time to do all the coaching and education that is critical for a living with a lifelong disease.

While the rheumatologists focus on controlling disease activity, the nurse practitioner meets with patients quarterly to emphasize wellness. She

asks questions like: Did you get your bone density study? Are you taking your calcium and vitamin D because you're on prednisone? How are you doing with sun avoidance? Do you understand the timeline of how your medicines are going to work? What are your plans for contraception? Do you need help accessing a primary care physician? She also organizes support groups so patients can meet other people who are dealing with similar challenges.

Lupus is common in New Haven. It is on the rise or being recognized more?

Lupus is more common and more severe in the Hispanic and African American communities and our Hispanic community is growing. Because there are many barriers to care for some of our patients, including insurance issues and transportation, we now have programs at Cornell Scott Hill Health Center in New Haven and we are initiating an e-consult service to the Fair Haven Community Health Center.

What else is notable about the program?

A critical step in development of the Lupus Program was the recruitment of Dr. Fotios Koumpouras, who joined the rheumatology faculty in the last year as director and leader of the clinical and clinical research program. He is the principal investigator of The Yale Rheumatology BioRepository, which captures longitudinal clinical data and biologic specimens for our patients involved with research. The program now offers the option for patients with lupus to engage in clinical research, coordinated interdisciplinary academic care.

Another critical piece was the recent designation of the Lupus Program at Yale as a member of the new Lupus Clinical Investigators Network (LuCIN) that comprises academic lupus centers in North America. The

Yale site is directed by Kang, the leader of the translational research group in lupus. He works with Dr. Koumpouras, with support of the basic research program in lupus at Yale. The goal of the LuCIN is to form a group of lupus clinical researchers to conduct focused, biomarker-rich, and proof-of-concept clinical trials to develop new lupus treatments in a comprehensive and speedy manner. In working with the LuCIN, the Lupus Program at Yale is going to conduct clinical trials testing the benefits of pharmacologic and non-pharmacologic interventions in lupus. Such treatments will only be available at select academic medical centers in the United States and Canada. We believe this provides an excellent opportunity to our lupus patients who want to participate in cutting-edge clinical trials to help not only them but also other lupus patients worldwide.

Another important step that I think really makes a difference is the Transition Program. Children and teenagers get lupus and are at risk for more severe diseases. We are working with Yale pediatricians Dr. Paul McCarthy and Dr. Ian Ferguson to transition their young adult patients with lupus into a special adult program that emphasizes education and shared decision-making. We see the pediatric patients who are ready to transition in the pediatric rheumatology clinic with Drs. McCarthy and Ferguson. That personal introduction makes a difference—it decreases the anxiety about transitioning to the adult providers and gives us a chance to learn abut medical and psychosocial issues that have been important in their care from their pediatric providers.

What are the symptoms of lupus and do they vary?

They vary a lot, which makes it hard to diagnose. The inflammation of lupus can strike just about any organ. If people develop arthritis or rashes it's more evident to them that something is wrong and they are more likely to see a doctor and get a diagnosis. But lupus may start with no symptoms. For example if a patient has inflammation of the kidney,

or vague symptoms such as fatigue or anemia, that can make it difficult to diagnose and so delay treatment. Blood tests can be helpful in diagnosis in such circumstances.

What about treatment? Is there anything new?

Benlysta, a medication that suppresses the immune response in lupus, is a promising new treatment, and it's the first new FDA-approved medication for lupus in over 20 years. Koumpouras is the principal investigator at Yale in a multicenter clinical trial to study the benefits and side effects of Benlysta over time. Many new medications are now in development and Koumpouras, working with Kang in the new Yale LuCIN center, will be bringing many of these new studies to Yale.

There are also safe, older antimalarial medicines such as hydroxychloroquine (Plaquenil) and other effective immune-suppressing medicines that are available. But treatment often requires a combination of medications and that is frustrating for patients, especially young people. And, for people with more severe disease, it can be difficult to completely control disease activity with these medications, which is why research is so important.

How did you get interested in lupus?

I have training in adult and pediatric rheumatology and since lupus affects people from childhood into adult life, my training has given me the opportunity to care for people over a broad age range. You form a bond with these teenagers and young adults as they navigate many of the important life decisions—relationships with peers, education, starting jobs, having children—with a chronic illness. Helping them to understand their illness, offering support through difficult periods, and working with them to help them become more independent in their

health decisions is a very rewarding experience.

Lupus is a very challenging disease to treat. So treatment requires close follow-up and coordinated care with other specialists. Working with other specialists—the dermatologists, nephrologists and pulmonary specialists (to name a few)—makes the work more interesting. Currently we are working with Dr. Sarika Ramachandran from Dermatology and Dr. Randy Luciano from Nephrology at Yale. It's a team effort, and we learn from each other about the latest developments in our fields and our personal experience caring for patients. Because of the excellent subspecialty programs at Yale and the support we receive from YNHHS, we are in a unique position to offer innovative multidisciplinary clinical and research programs for people with complex medical conditions such as lupus.

Provided by Yale University

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