

lupus foundation of northern california

newsletter

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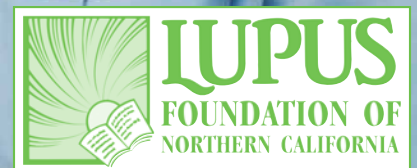
Lupus
drugs in the
pipeline

Protecting
your skin from
the sun

Know the
symptoms
of lupus



TAKING ACTION AGAINST LUPUS



Taking action against lupus

STORY BY PATRICIA S. CULPEPPER
FOR THE LUPUS INITIATIVE

Ivana Ford-Neal was diagnosed with lupus nearly 30 years ago at age 15. Her story is one of misdiagnosis, varying access to care, battling insurance companies, frustration, and eventual victory. She shares her story freely in hopes of bringing more attention to lupus, encouraging others with the disease, informing healthcare providers, and enlightening the general public about this potentially devastating disease.

Dealing with lupus is a complex process that takes patience and perseverance. Here's one patient's story about the difficulty of diagnosing the disease — and the roller coaster ride that came after

Ivana wants others with lupus to know that it is possible to get the disease under control and live a rich life that includes family and career

Lupus affects up to 1.5 million people in the United States. While not a rare disease, especially among women and people of color, it is still misunderstood by many, and the average time-to-diagnosis from onset of symptoms is four years. The difficulty in diagnosing lupus can be attributed to a number of factors including the complexity of the disease, the wide range of symptoms that are also common to many other diseases, and the fact that there is no single, definitive test for lupus.

Ivana Ford-Neal's lupus initially manifested as a facial rash. She recounts the heart-wrenching story of leaving one doctor's office in tears after he dismissed her rash as a normal occurrence for African Americans and told her it would pass. Another doctor tried to remove her facial lesions by burning them off. A dermatologist, Dr. Leah Press, eventually diagnosed her. Ivana remains grateful to Dr. Press to this day.

Following her diagnosis, Ivana joined a lupus support group, but there were no other African Americans in the group. She says it would have helped her to meet someone early on who looked like her. Finding no one she could relate to in her support group, she turned to cancer patients for inspiration when she lost her hair. Being that role model for others is part of what motivates Ivana today. Increasing general awareness about lupus is also important to her. Many people don't understand the serious nature of lupus and the potentially devastating effects; therefore, getting the support you need from employers can be difficult.

Ivana wants others with lupus to know that it is possible to get the disease under control and live a rich life that includes family and career. Ms. Ford-Neal is a wife and mother and loves teaching first-grade in Fresno, California. Her lupus is now well managed, and she attributes her current success to the unwavering support of her family through the years, an understanding and supportive work environment, and an outstanding team of physicians.

There were many trying times for Ivana when she first became ill and in the years following her diagnosis. But in recent years, her situation has greatly improved, due mostly to her current team of doctors. Having physicians who understand lupus, how to treat it, and how to relate to lupus patients has made all the difference. When asked what she most wants healthcare professionals to know about treating lupus patients, she shared the following points.

LISTEN

Ivana spoke with gratitude about her current medical team and their willingness to listen. When she first saw her current primary care physician, Dr. Helen Jones of Fresno, Ivana talked, and the doctor listened, without leaping to conclusions based on her training or prior experience. When Dr. Jones referred her to a team of specialists at the University of California, San Francisco (UCSF), Ivana was met with a similar experience. Ivana was impressed that these expert physicians all took the time to listen.

PARTNER WITH YOUR PATIENT

Ivana is able to work in partnership with her current medical team. Options are discussed and explained, and she is involved in decision-making. If needed, her doctors help her do battle with her insurance company, providing justification for prescribed drugs and treatments.

TALK TO EACH OTHER

Ivana's primary care physician does not hesitate to pick up the phone to contact her rheumatologist, Dr. Maria Dall'Era at UCSF. In addition to Dr. Dall'Era, Ivana's medical team at UCSF includes two dermatologists and a nephrologist. Ivana appreciates that they routinely speak with each other to discuss her case.

BECOME AWARE OF YOUR OWN BIASES AND PREJUDICES AND WORK TO ELIMINATE THEM

Thirty years later, Ivana is still pained by her experience with the physician who dismissed her condition as normal for African Americans.

Ivana Ford-Neal's commitment to advancing the cause of lupus and spreading awareness about the disease includes working with The Lupus Initiative (TLI), a multi-faceted program led by the American College of Rheumatology. TLI's primary goals are to provide education to medical professionals in order to increase their knowledge and awareness of lupus and to promote early detection and effective treatment of the disease for all patients, regardless of age, gender, race, ethnicity, or socioeconomic status. Towards that end, TLI has developed tools and resources to assist medical professionals, educators, students and patients.

Just last month, The Lupus Initiative launched a comprehensive set of educa-

tional resources aimed at advancing the care of people with lupus. These educational materials were developed to assist medical providers, educators and students in the diagnosis, treatment, and management of lupus. "In keeping with TLI's mission, the newly launched materials not only highlight the issue of health disparities in lupus and the importance of eliminating bias in patient care, but also provide tools and practical guidance towards achieving those objectives," said Sam Lim, MD, MPH, Consortium Chair of The Lupus Initiative.

TLI also provides resources for lupus patients. These resources include general information, fact sheets, frequently asked questions, a symptom tracker, and a mobile app. The app, called Lupus Companion was designed specifically for lupus patients to help them manage their own disease and facilitate communication with providers by assisting them in monitoring symptoms, triggers and flares between office visits. The app allows patients to log information about symptoms, doctors' contact information and appointment times, and medications. By keeping track of this information in one, easily accessible place, patients can provide more comprehensive information for healthcare providers during appointments. The app is currently available by request and will soon be available for download, free of charge, on iTunes for iPhone and iPad users. Look for it on iTunes this summer.

For more information on The Lupus Initiative and to access any of these resources, visit their website at www.lupusinitiative.org.