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Desert Leaf

The Catalina Foothills Magazine

Livin' Large in a TINY HOUSE

With Support From the Lupus Foundation of Southern Arizona

by Jan Henrikson


Photos courtesy: Lupus Foundation of Southern Arizona

The 2015 Walk the Loop for Lupus

A weekend of laughter, meditation, and horseback riding is not a cure for lupus, but it can make you feel strong and free and not alone.

That's exactly what the Lupus Foundation of Southern Arizona (LFSA) had in mind for the women who attended its inaugural Women's Retreat at the White Stallion Ranch in October 2015. Retreat participants left "rejuvenated, knowing they're not going to die. They're going to be okay," says Rebecca Shields, president of LFSA. "We already have a group of women who can't wait for the next one."

Of the 1.5 million Americans diagnosed with lupus, a mysterious autoimmune disease with no known cure or cause, 90 percent are women between the ages of 15 and 44. Few had heard of lupus when Shields was diagnosed in 1985 at 25. "It was very isolating," she says. "Most people don't talk about it because it presents differently for everybody. It's not a cookie-cutter illness where you show ABC symptoms. That's what makes it such an enigma."

With lupus, as in all autoimmune diseases, the immune system stops differentiating between foreign substances (antigens) and its own cells and tissues, and begins attacking the body it was designed to protect. Getting a diagnosis can be tricky and time-consuming because the symptoms of lupus—fatigue, low-grade fever, weight loss, a butterfly-shaped rash extending across the cheeks and bridge of the nose, inflammation of the joints and kidneys, photosensitivity, anemia, headaches—come and go, and mimic other diseases.


LFSA's 2015 gala attendees place their bids at the silent auction.

For eight months, Shields couldn't figure out why she was losing weight, was fatigued, was suffering with so many migraines, and had swollen glands and nodules in her neck. Finally, she was hospitalized with major kidney damage. "When you're that sick, it's an out-of-body experience," she says. "It's been a long journey, full of ups and downs."

As a clinical psychologist told Shields when she was first diagnosed, "You need to be like a tigress. You need to fight very hard to stay alive." Today Shields and LFSA are on fire to make sure no one with lupus feels isolated—or powerless—again. Caregivers and lupus patients who walk through LFSA's office doors at 4602 E. Grant Road are met with compassion, empathy, and a variety of services, from a lending library to Medicare and insurance counseling.

Sharon Smiley (office manager) and Luci Ponticelli (grants and finance) "are really a conduit between them [the lupus patients] and their physicians," says Shields. "They help patients become their own best advocates."

To that end, LFSA offers one-on-one counseling, bilingual support, and two support groups open to lupus patients and caregivers alike. The third Wednesday of every month at 10 a.m., Helen Butler, a registered nurse living with lupus, facilitates a group exploring ways to care for oneself as one ages, among other topics. Coffee Talk, a new evening support group, gathers the first Wednesday of every month at 6 p.m. Although the group is open to every age and demographic, it typically speaks to a younger audience, often newly diagnosed. Attendees share their questions and feelings about lupus.

How do you figure out the best medical support for your unique mix of symptoms? How do you learn to accept your body's new limitations?

"You have to understand that you can't get out in the sun anymore. You need to rest. That's hard for some people when their body shuts down at two in the afternoon. They keep going and stress themselves into a flare. You have to take good care of yourself to stay healthy," says Shields.

A part of taking good care of yourself is getting good information. While hormones, genetics, environmental factors, and stress are the four factors most strongly correlated with the onset of systemic lupus erythematosus (SLE), the most common form of lupus, no one did anything to cause their disease.

"Since there is no known cause, as a lupus patient you always wonder, what did I do to make this happen?" says Shields. "Smoking can lead to emphysema. Drinking can lead to cirrhosis." Dr. Bridget Walsh, a rheumatologist, and speaker at LFSA's first gala fundraiser last November "assured us that no one did anything for their lupus to happen. It was wonderful," says Shields. "I'd never heard anybody say that."

The gala raised money to support LFSA's emergency medical fund as well as its limited scholarships to qualified

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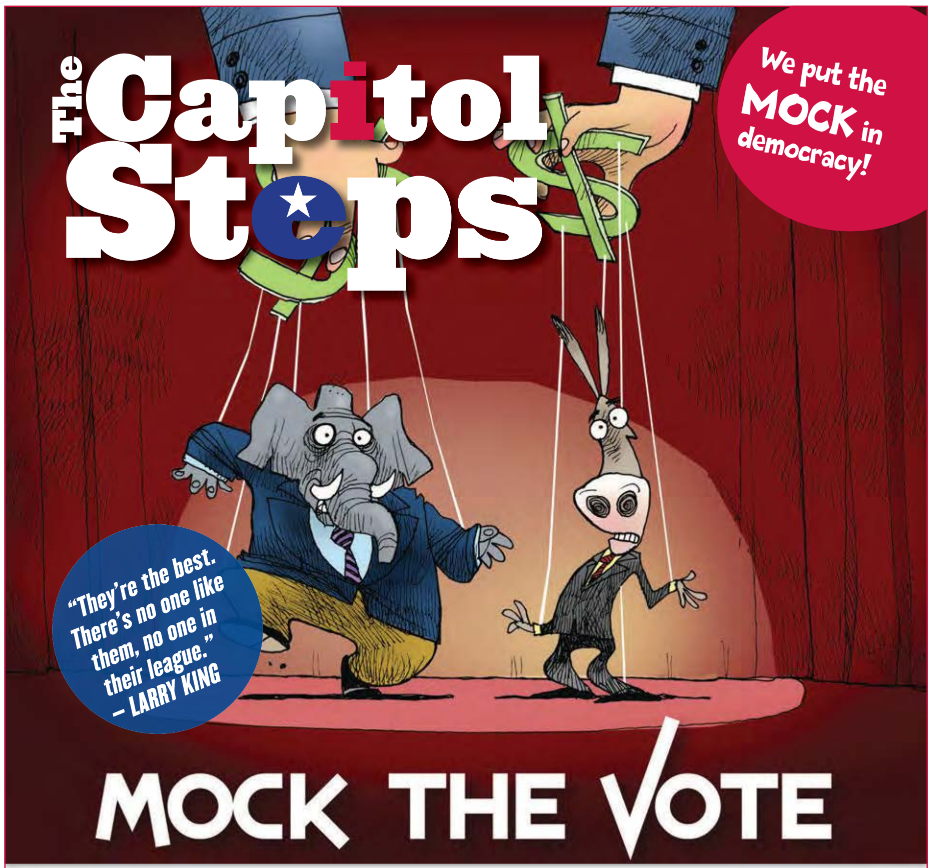

NEW TRANSPORTATION LAWS continued

passengers, while another law allows for a motorcycle, ATV, or motorized cycle to have handlebars that extend higher than the shoulder. In the 1970s and '80s, such handlebars were popularly known as "ape-hangers."

Three new specialty license plates were made available in 2015. Of each plate's $25 annual fee, $8 is an administrative fee and $17 is a donation to benefit the efforts of either nonprofits, charities, colleges, or emergency responders.

Donations from the sale of an Arizona Coyotes plate go to the Arizona Coyotes Foundation, which supports nonprofit organizations that promote healthcare, education, and cultural arts programs for children and military service men and women. Donations from sales of the Midwestern University plate go to scholarships for students studying health sciences at Midwestern University. Donations from sales of the U.S. Marine Corps plates go to the U.S. Marine Corps Scholarship Foundation and benefit children of Marines and Navy Corpsmen killed or wounded in combat or those children who have demonstrated financial need. Donations from sales of the Firefighter Safety Training plate provide scholarships for life-safety training of firefighters in Arizona.

Community-college collegiate license plates are now in the design phase. ADOT is authorized to issue collegiate specialty license plates that identify each community college in a community-college district with a full-time-equivalent student enrollment of more than 50,000 students. The $17 donation goes to the Community College District Collegiate Special Plate Fund. Each community college district with the required student enrollment must establish a separate Special Plate Fund, and monies going into the fund from license plates must be used only for academic scholarships.

A list of Arizona Revised Statutes relative to transportation laws can be found at azleg.state.az.us/ArizonaRevisedStatutes.asp?Title=28.

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HEART OF THE MATTER continued

candidates seeking to continue their higher education. To reach out to more people in hospitals and doctors' offices, LFSA is planning to create a magazine like *Arthritis Today*, filled with local and national information about clinical research trials, new treatments, and current events for lupus patients, their families, and caregivers.

Shields considers her joining the LFSA board two years ago her coming-out party. "It was very cathartic," she says. "I can be a role model for people coming to the [LFSA] door who are scared out of their minds. 'Hey, you're going to be okay. I've had it for 30 years. I have an MBA, a career, I'm happily married, and I have lupus. It's been challenging, don't get me wrong. But I'm not defined by my disease. I cherish every day.'"

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2016 Walk the Loop for Lupus

Saturday, April 23, 2016
Reid Park
Tickets: $25 per person preregistering at the LFSA office, 4602 E. Grant Rd., M–F, 9 a.m.–2 p.m., or online at www.lupus-az.org; $30 if registering at the walk. For more information, call 520-622-9006 or email info@lupus-az.org.