



THE SEMI-ANNUAL PUBLICATION OF LUPUS LA

SPRING/SUMMER 2017

Selena Gomez, Nick Cannon, Toni Braxton and Seal

ALL HAVE LUPUS

Board Members Janet Janjigian and Adam Selkowitz co-authored this article published in the Huffington Post in March of this year, with support from our Lupus LA program manager, Katherine McMahon. It profiles two lupus patients and details what will happen to lupus patients if the Affordable Care Act is repealed. The article has received national praise and helped continue to keep healthcare in the front of everyone's minds. In case you have yet to read this impressive piece, we included it in its entirety below. Please share it with your family and friends. If you would like to comment or have a question, please send it to us at info@lupusla.org. Enjoy!

Selena Gomez, Nick Cannon, Toni Braxton and Seal all have Lupus. So do Mercedes Ibarra and Kikki Eder and for these two who saw marked improvements under ACA, dropping the vote to repeal and replace it last week still leaves them frightened about their healthcare future.

Kikki Eder is 61 years old, formerly employed full time as an internal healthcare auditor for a hospital. After being laid off from her job in 2008 because of hospital cutbacks, she pursued a new career as an artist, fiercely pursuing a way to continue working and supporting herself. Eder was enjoying success as an artist until 2012, when she was diagnosed with lupus, suffering constant joint pain, fatigue, pleurisy, brain fog and anemia.

In 2013, her lupus became so debilitating she could no longer work at all. Her medical costs were overwhelming, premiums alone were over \$800.00 a month, and since lupus is considered a pre-existing condition, she could not get affordable insurance. She was living on money saved for her retirement and help from family.

(Continued on pg. 3)



MAY IS LUPUS AWARENESS MONTH

Join millions of lupus patients from around the country as we celebrate lupus awareness. Share your story with someone new or thank those around you for their love and support. Over 1.5 million Americans have lupus. Let's work together to spread awareness and hope. For more information on lupus, please visit www.lupusla.org.

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Want more Lupus LA? Check out what's happening at WWW.LUPUSLA.ORG.

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Letter from the Chairman



Dear Friends,

For 18 years I have helped guide Lupus LA through dozens of events geared toward raising money for our programs and research. For each of those events we've had people who step up and agree to be honored by our organization. I've worked hand in hand with all of our honorees over the years, but this year was my turn. I had the pleasure of being honored with the 2017 Loop Award at the Orange Ball this past April. There's nothing quite like the experience and it gave me a very different perspective than I previously had.

I'll say this, it's a lot of work and, in order to be successful, it's also a big commitment from your family, friends, and colleagues and I want to thank all of mine for taking the journey with me. Without that support system not much gets accomplished. I am incredibly grateful to all those who made a donation, took an ad in the journal, or joined us underneath Space Shuttle Endeavor for a truly special evening. In conjunction with my fellow honorees and the rest of the Lupus LA board, we had a very successful night, raising over \$650,000 for Lupus LA.

Being an honoree has allowed me to reflect on my time at Lupus LA, and while we have come a very long way in 18 years, we need to do more. We need to raise more research dollars, more patient dollars, and more lupus awareness, and that's why I want to encourage other Lupus LA supporters to expand their relationship with us. Consider joining an event committee or volunteering at one of our events. Let us know if you're interested in learning more about the multitude of opportunities to get involved and to contribute. Our board of directors is always looking for those dedicated supporters to help guide the organization into the future. Could that be you? Are you our next honoree?

In my speech to the audience at the Orange Ball I talked about being underneath the space shuttle and that those who rode in that shuttle live for the mission. That's how we think of it at Lupus LA — we're on a mission to treat and cure this disease and we need you to become one of our astronauts. For more information, please call the Lupus LA office or visit our website. Again, thank you very much for honoring me this year — it was an out-of-this-world experience!

Best wishes,

HUFFPOST on Lupus (Continued from pg. 1)

"The ACA and Covered California has been a Godsend," said Eder. "It has made a difference because lupus has affected my life in every way possible physically, emotionally, financially, socially. I would never be getting the treatment from the doctors I can see now without it, it's incredible. I'm functioning so much better with this level of medical care, I can make plans, do errands and leave the house."

Even though the vote to repeal and replace the ACA was dramatically pulled minutes before the vote was to take place, Eder remains skeptical about future healthcare overhaul.

"Covered California has been a godsend."

"I'm deeply concerned about what may come, I think this is only a temporary relief. I don't trust or have any confidence in what may happen to those of us with chronic diseases, they don't care about us at all," she said.

Currently, Eder pays \$294.00 a month for her PPO plan under Covered California, the pre-existing stipulation for lupus no longer an issue under the ACA, and a \$3 co-pay for the more than 6 medications she takes. She was denied disability, consulted a lawyer to appeal the decision and has been waiting more than a year and a half for a hearing date.

"I don't trust or have any confidence in what may happen to those of us with chronic diseases, they don't care about us at all."

Lupus affects 1.5 million Americans and more than 5 million globally. Lupus attacks the immune system, causing pain, inflammation, organ and tissue damage, extreme fatigue and can target anywhere in the body including causing serious facial skin rashes from the sun. Nearly 90% of lupus patients are women, the onset of the disease usually occurring between the ages of 15 and 44, with African-Americans 3 times more likely to get lupus than Caucasians and Latino women 2 times as likely to be

hit. It is the leading cause of stroke, heart and kidney disease among young women and the number of patients diagnosed with lupus is growing yearly, especially among children and teenagers. In addition, there are few similarities between patients with lupus, it affects each individual differently, often making a firm diagnosis difficult for those who do not have access to specialists.

There is no cure for lupus, and we at Lupus LA, including Toni Braxton who is on our Board, are working hard to raise awareness to fund research to find a cure for this little known, major disease that is more common than MS, Cerebral Palsy and Cystic Fibrosis combined. Since 2000, Lupus LA has raised more than \$10 million to fund research, create support groups and assist those diagnosed with lupus with critical medical information, patient conferences to meet doctors and specialists, scholarships for those in need, emergency grants and refer doctors. With global reach and recognition while based in LA, Lupus LA has become the "go to" for the latest in research regarding new drug therapies, world renown doctors and researchers, support systems and a staff committed to reaching out to everyone who has a question about the disease. (www.lupusla.org)

"The goal at Lupus LA is to be comprehensive and invaluable."

"Lupus LA has been a great resource for me since 2012," said Eder. "There's a support group in my area where I can get the latest information on new drugs, recommendations for doctors and specialists, meaningful coping strategies, resources and sharing symptoms with others who suffer from lupus."

(Continued on pg. 8)

WE'RE OVER THE MOON!

For the Lupus LA Orange Ball: A Rocket to a Cure

Over 400 guests ROCKETED TO A CURE at the 2017 Orange Ball held on Saturday, April 22nd, at the California Science Center. Participants dined under Space Shuttle Endeavor on delicious creations from event sponsor The Kitchen for Exploring Foods, including the signature drink the *Buzz-ed Aldren*. Also on deck was Polite in Public who provided a fun, out-of-this-world photo booth experience for our guests.

Honored this evening were the innovative pharmaceutical company Eli Lilly for being leaders in lupus research, powerhouse media couple and philanthropists Marta and Ron Bloom, and founding member and Chairman of the Lupus LA Board Adam Selkowitz.

On hand for the evening and serving as our celebrity auctioneer was Lupus LA Ambassador Sharon Stone. She reached for the stars and got us over the moon by helping to raise over \$100,000 in the room that night with our live auction and impromptu cash call.

Overall, Rocket to a Cure raised over \$650,000 to help find the causes of and a cure for lupus through supporting research, patient programs, and advocacy and awareness campaigns.



For photo credits, please see page 5.



BAGGED IT!

at the Hollywood Bag Ladies Luncheon

The 14th annual Hollywood Bag Ladies Luncheon was in full swing this past November. Over 500 guests took part in a unique shopping and fashion event at The Beverly Hilton to raise money for medical research and the programs of Lupus LA. Honorees were *Extra* host and Lupus LA Ambassador Terri Seymour, mother-daughter duo Sheila Millstein and Nicole Fogel and volunteer extraordinaire and TV executive Joan Robbins. Raising over \$365,000, guests viewed a fashion show by Salvatore Ferragamo and were treated to a small show preview with a live model tableau in the silent auction room. One-of-a-kind live auction packages were sold by the charismatic Jenni Pulos - raising an additional \$32,000 for the cause.

This year's event heralded a total of 255 bags with highlights being from Ferragamo, Louis Vuitton, Balenciaga, Dior, Roberto Cavalli and more. Next year's date has already been set for:

Friday, November 17, 2017

SAVE THE DATE

and you've got it in the bag!



BAGGED IT! (top L to bottom R): Event host Jon Kelly, Bag Ladies committee member Janice Arouh, event honoree Joan Robbins, Lupus LA supporter Carolyn Folks, and Board Chairman Adam Selkowitz get ready together on the orange carpet; Award presenter and songstress Leona Lewis with luncheon honoree and Lupus LA Ambassador Terri Seymour; Mother-daughter honoree duo Sheila Millstein and Nicole Fogel; Auctioneer extraordinaire Jenni Pulos and Bag Ladies committee member Noah Alexander; Award presenter Eden Sassoon and mother, Beverly Sassoon; Fashion presentation by Salvatore Ferragamo.

WE'RE OVER THE MOON (top L to bottom R): Board Member Lauren Shuler Donner delivers the state of the agency; Honorees Marta and Ron Bloom; Board Members Janet Janjigian and Dorothy Ellis; Honoree and Board Chairman Adam Selkowitz celebrates with his wife, Laurie, and friends, Yanaika and Paul Harrigan; Lupus LA Ambassador Sharon Stone delivers as

our celebrity auctioneer for the evening; Our youngest guest of honor, Lucy Rae Selkowitz, walks her first orange carpet with dad Adam; Walking the carpet with guests Jimmy Walker, William Brinton, Trish McCrone, Clif Loftin, Lupus LA Ambassador Gilles Marini, Carol Marini, Kelly Stone-Singer, Bruce Singer, Lupus LA Ambassador Sharon Stone, and Victoria Noyes; Accepting the award for Eli Lilly and Company is Dr. Ajay Nirula with his wife and son, Lisa and Michael; Guests enjoy the Polite in Public out-of-this-world photo booth. Pictures here (L to R) are: Midwest lupus advocate Dina Thachet and Lupus LA support group leader Lauren Irving; Past Lupus LA fellow and Medical Advisory Member Dr. Vaneet Sandhu and husband Gary; Lupus LA volunteer Silvia Masera and Lupus LA program manager Katherine McMahon; Lupus LA Ambassadors Ali Hillis and Meredith Monroe.

Latest on Lupus with Dr. Daniel J. Wallace: Advances in Research

According to PubMed, the repository of all medical articles written in the peer review literature, there were 3,540 articles published on lupus in 2016 in recognized medical journals. Although they covered a variety of topics, this column focuses on three that this writer believes to be of particular interest.

WE MIGHT HAVE LUPUS IN THE KIDNEY (LUPUS NEPHRITIS) ALL WRONG

Kidney structure consists of the glomerulus which performs the filtering function of the kidney and is connected to tubules, or small canals which transport waste to the ureters, and ultimately the bladder for excretion. For over 50 years, doctors have associated inflammation of the glomerulus with lupus and identified tissue types under the microscope that are associated with disease activity and outcomes. Recently, it has been shown that the tubulointerstitium, or tubules and the tissue around them, are more important and may be the location of tissue inflammation. Nephrologists and rheumatologists are now looking at markers of this, which, over the next 5 years, will totally change the way we treat lupus kidney disease.

A NEW ADDITION TO UNDERSTANDING LUPUS TREATMENT: THE KINOME

The human kinome controls much of intracellular cell signaling that directs how proteins and their enzymes signal how a cell behaves. There are over 500 kinases in our kinome. Until recently, lupus researchers paid little attention to this. There are several families of kinases that influence inflammation. These have names such as Syk, BTK, JAK and tyrosine kinase inhibitors. The first drug to block JAK was introduced two years ago to manage rheumatoid arthritis and is known as tofacitinib (Xeljanz). Improvements in our knowledge of kinome biochemistry have been rapid, and no fewer than 10 such molecules are being studied in lupus clinical trials.

GENETICS IS IMPORTANT, BUT THE EPIGENOME AND HORMONES MAY BE MORE IMPORTANT

If a woman with SLE has an identical twin sister, the chances that her twin will also develop lupus is 25%. This suggests that environmental factors and hormonal factors account for the majority of lupus. Recent studies have suggested that tobacco smoke, pollution, ultraviolet light from the sun, and especially dietary factors play a role. The bacterial makeup of our gut, known as the microbiome, differs from person to person. Recent work suggests that a part of the epigenome, whereby heritable or acquired modifiers of DNA without any change in the DNA base sequence can alter immune function. This includes a process known as methylation. Hypomethylated diets may flare lupus in certain mouse strains. Also, recent work has suggested why more women develop SLE. It appears that the X sex chromosome (females are XX and males are XY) in combination with T cells might upregulate the immune response. In other words, non-genetic factors may promote and flare lupus.

"This is an exciting time in lupus research and with your support, further advances will be made." - Dr. Daniel J. Wallace

Find a Group

Lupus LA's support groups are a great resource for people living with lupus and their loved ones. Join us at one of the following groups to learn more about lupus and how to live well with this chronic illness. Our support groups are free, confidential, and open to the public. For more information about the Lupus LA adult support groups and our pediatric support group at Children's Hospital Los Angeles, please contact Lupus LA at 310-657-5667 or via email at kmcMahon@lupusla.org.

Looms 4 Lupus Support Group Second Saturday of the month From 9:30 AM to 11:30 AM

Kaiser Permanente, Educational Outreach Program
4141 Maine Avenue
Baldwin Park, CA 91706

Crenshaw Support Group Second Tuesday of the month From 7:00 PM to 8:30 PM

West Angeles Church
Multipurpose Bldg., Rm 7
3045 Crenshaw Boulevard
Los Angeles, CA 90016

Spanish-Language Support Group

**Primer Jueves del mes
De 7:00 PM a 8:30 PM**

Clinica Oscar Romero, Sala 35
2032 Marengo Street
Los Angeles, CA 90033
(En frente del hospital general de USC)

Support Near You

Alhambra Support Group
Third Tuesday of the month
From 6:30 PM to 8:00 PM
 Alhambra Civic Center Library
 2nd floor Conference Room
 101 S. First Street
 Alhambra, CA 91801

UCLA Support Group
First Tuesday of the month
From 6:30 PM to 8:00 PM
 Rheumatology - Rehabilitation
 Center Building
 3rd Floor - Library
 1000 Veteran Avenue
 Los Angeles, CA 90024

Sherman Oaks Support Group
Second Tuesday of the month
From 6:30 PM to 8:00 PM
 Circle of Care Conference
 Room, Sherman Oaks Hospital
 4929 Van Nuys Boulevard
 Sherman Oaks, CA 91403

Long Beach Support Group
Fourth Tuesday of the month
From 6:30 PM to 8:00 PM
 Miller Children's Hospital Long
 Beach
 Children's Hospital Pavilion,
 Conference Room B
 2801 Atlantic Avenue
 Long Beach, CA 90806

Irvine Support Group
First Monday of the month
From 7:00 PM to 9:00 PM
 University United Methodist
 Church
 18422 Culver Drive
 Irvine, CA 92612

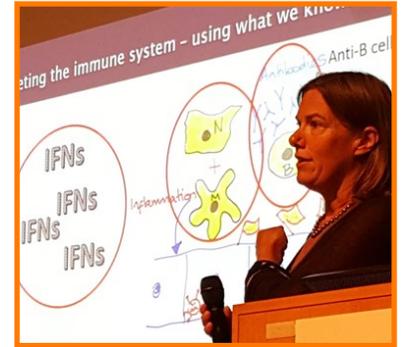
GROUP OF THE MONTH:
Howse Foundation &
Lupus LA Support Group
Second Saturday of the month
From 11:30 AM to 1:00 PM
 Olive Branch Diagnostic
 Imaging
 Women's Health Center
 10722 Arrow Route, Suite 520
 Rancho Cucamonga, CA 91730



Latest on Lupus: The Los Angeles Patient Conference

Our annual *Latest on Lupus* Los Angeles patient conference was held on October 15, 2016 at the UCLA Medical Center. The conference brought together a wide range of lupus patients, along with their loved ones, who were eager to learn more about the latest developments in lupus treatments. The attendees reported that the conference served as an exciting opportunity for them to hear from the best and the brightest in the field of lupus research and care.

The conference covered the most up-to-date research and treatments of lupus. Dr. Daniel J. Wallace, attending physician in the division of rheumatology at Cedars-Sinai Medical Center and a clinical professor of medicine at UCLA's David Geffen School of Medicine, presented the *Latest on Lupus*. Dr. Wallace's informative presentation was followed by a helpful question and answer session. Many conference attendees shared that they are appreciative to have had the opportunity to ask questions to an expert rheumatologist, like Dr. Wallace.



Dr. Jeffrey talks about immunology.

Next, there was an advocacy panel discussion with Juana Mata, CSW, Liz Morasso, LCSW, and Jessica Rowshandel, LMSW. The panelists empowered the audience by sharing their personal journeys with advocacy work as well as with helpful self-care information. The attendees were pleased to learn more about how they could get involved and felt motivated to create more opportunities for advocacy work.

After lunch, Elizabeth A. Prescott, M.D.H. Certified Breathing Coordination Practitioner and Vocal Consultant, presented M.D.H. Breathing Coordination: Maximum Efficiency, Minimum Effort. Conference attendees learned important posture and breathing techniques.

The patient conference culminated with Dr. Caroline Jefferies, Medical researcher, presenting helpful information about Immunology. Many conference attendees shared they were grateful to learn about such an important topic.

We would like to thank our sponsors, Mallinckrodt and PhRMA, who enabled us to host the informative conference to patients and their families. We are looking forward to our next *Latest on Lupus* patient conference which will be held on June 3rd at UC Irvine. For more information, please email us at kmcMahon@lupusla.org, or call our offices at 310-657-5667.

HAVE AN OLD CAR AND NEED TO GET RID OF IT?

Donate it to Lupus LA. You will get a tax write-off and Lupus LA will get a donation. Contact our partners at www.donateforcharity.com and schedule your pick-up today.



HUFFPOST on Lupus (Continued from pg. 3)

"The goal at Lupus LA is to be comprehensive and invaluable. We work directly with lupus patients and their families to help them navigate the challenges of their disease and we also work to raise worldwide awareness through our celebrity ambassador program to help educate the public about lupus," said Adam Selkowitz, Chairman of Lupus LA.

Mercedes Ibarra enjoyed an active, full time career in the entertainment industry as a Flamenco dancer, spending her evenings and weekends performing in Spanish restaurants and theatres. Recently diagnosed with lupus, the 40 year found it harder and harder to continue her work.

"It (ACA Coverage) has made a huge difference. It was the first time I've been to the doctor in years."

"I was having crushing fatigue, severe muscle pain, migraines, hair loss, heart palpitations, high fevers and pelvic floor dysfunction making it harder and harder to dance," said Ibarra. "I had to pare down my work, spending most of the week in bed and trying to work on the weekends." When she couldn't keep up her theatre and restaurant commitments, Ibarra turned to teaching dance two days a week. "The kids I teach know I have lupus," she said. "I'm trying to continue to work while managing my symptoms."

"I'm still frightened even though the vote to repeal and replace was pulled."

Ibarra credits Lupus LA for helping her find doctors at patient conferences. "The support group I attend once a month has had a big impact on my life. I've made friends who have been great, we share our experiences and how lupus impacts our families, our work, and it's a new crossroad for me. I got great information at a patient conference that led me to a cardiologist and this has helped me a lot."

Ibarra signed up for ACA coverage under Covered California in 2014. "It has made a huge difference. It was the first time I've been to a doctor in years, I couldn't get coverage before. And the only reason I can do any teaching at all now is because the medical treatment I'm getting now is great, it's helping me feel better so I can work." she said.

Ibarra just got an increase for 2017 under the ACA, now paying \$294.06 a month, with a \$3 co-pay for the 5 different prescription medications she needs, as opposed to the \$800 or \$900 a month on the open market, if she could get insurance. "I'm still frightened even though the vote to repeal and replace was pulled," she said. "I'm sure they still want to replace it, but with what, I haven't seen anything that provides the same level of access I have now, plus it is more expensive with less coverage."

"I am very worried about the possibility of going backwards to a time where such programs didn't exist."

"Since the affordable care act has been in place in California, I have seen my patients have improved access to insurance and healthcare. They have also been able to contemplate different job options without fear of losing the health benefits. The variety of plans available has allowed patients to look for programs that best fit their needs," said Dr. Jennifer Grossman, Rheumatologist and member of the Lupus LA Medical Advisory Board. "I am very nervous about the possibility of going backwards to a time where such programs don't exist. If this happens, our patients will suffer."

(Continued on pg. 9)

Lobby Trip to Washington, D.C.

Advocacy Update

On March 21, 2017, two members of the Lupus LA team went to lobby on Capitol Hill in Washington, D.C. The trip was organized by the Lupus Research Alliance (LRA), our research partner, and included lupus groups from all over the country. We met with the offices of Congress members Adam Schiff, Lucille Roybal-Allard, Ted Lieu, Brad Sherman, Maxine Waters, Alan Lowenthal, and Grace Napolitano. We described the impact of lupus on our lives and the lives of others. Then we asked them to support legislation and initiatives that concern lupus patients. This year, we had three main asks. We asked that the proposed healthcare reform include core principles for protecting people living with lupus. We asked for support of a \$2 billion increase to strengthen biomedical research at the National Institutes of Health. And we asked for support of \$5 million for the Lupus Medical Research Program in the FY 2018 Defense Appropriations Bill. We are very happy to report that multiple members of the California Democratic Delegation agreed to join the Congressional Lupus Caucus.

HUFFPOST on Lupus (Continued from pg. 8)

According to the latest Congressional Budget Office Report, **more than 24 million fewer people will have coverage over the next decade if the ACA is overhauled, which again is currently being discussed, 14 million of those alone by next year if new action is taken**, Eder and Ibarra likely among them. Without an immediate plan in place to cover those 24 million, they will be unable to sustain their current health status, with little chance for improved wellness, re-gain jobs and input into society. Under the ACA, they are paying less for coverage, getting better quality, more comprehensive, accessible care, resulting in marked improvements in their conditions.

Both women expressed concern that the perception of the ACA is that "it is some sort of giveaway, which it is not," and also want those reading this to know they have held jobs, worked hard to support themselves and families, paid taxes and been responsible citizens. Rather, it is their medical condition that prevents them from working full time to get employer sponsored insurance and without their current insurance, all of the progress they have made improving and managing lupus, will send them spiraling backward, and their overall health will regress. Without the ability to get better, sustaining affordable healthcare becomes nearly impossible, thus increasing the cost for all of us.

"I've had a lot of stress over this," said Eder. "My life depends on this insurance, and if it all goes away, this leaves me up in the air. Since lupus is a pre-existing condition I may not be able to get any insurance at all, then what am I supposed to do, leave the country?"

About the Authors

Janet Janjigian, Media and crisis communication strategist, Emmy award-winning TV news and documentary producer, former SVP of Corporate Communications at MGM Studios, and Board Member, Lupus LA.

Adam Selkowitz, CEO, Waterfall Films and Board Chairman, Lupus LA

Katherine McMahon, Program Manager, Lupus LA

LATEST
on LUPUS
PATIENT CONFERENCE

UC IRVINE SATURDAY JUNE 3 REGISTER AT WWW.LUPUSLA.ORG



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E: info@lupusla.org

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www.twitter.com/lupusla
www.instagram.com/lupusla

Lupus LA is dedicated to finding the causes of and a cure for lupus, while offering support to people with lupus throughout Greater Los Angeles.

SAVE THE DATE



presents the first ever

MBJAM17

Hosted by Lupus LA Ambassador
Michael B. Jordan

Join us for a family-fun courtside carnival at
The RITZ-CARLTON, Marina Del Rey

July 15th 5:30 pm

For more information, please visit our website
www.lupusla.org

