

Our Mission: To advocate for those affected by lupus and allied diseases through awareness and research program initiatives to improve quality of life.

Lupus Communiqué

Lupus and Allied Diseases Association, Inc.

Volume 12, Annual Edition 2015

ANNUAL RESEARCH DONATION



Lupus Research Institute Chairman Robert Ravitz (left) receives our Annual Research Donation of \$10,000 from Lupus and Allied Diseases Association President & CEO Kathleen Arntsen (right) on October 17th at the Alliance for Lupus Research / Lupus Research Institute Annual Scientific Meeting in New York. We are extremely proud that we have invested \$281,000 over the past 14 years by supporting novel, innovative and successful lupus and autoimmune research at the LRI.

Lupus and Allied Diseases Association, Inc. is a tax-exempt charitable organization eligible to receive tax-deductible contributions under IRS Code Section 501(c)(3). Our federal tax identification number is 16-1083229 and a copy of our latest annual report may be obtained upon request from us or The NYS Attorney General's Charities Bureau at 120 Broadway, NY, NY 10271.

Since we are no longer collecting membership dues, please consider Memorial and Tribute contributions to our organization. It is a wonderful way to honor or remember someone special in your life while also supporting the cause. If you belong to a Service or Fraternal organization, or participate in a workplace-giving program such as: SEFA, UNITED WAY, IBM or other campaign, please remember to designate our organization..

EDITOR'S NOTE

Suggestions or comments on the newsletter are always welcome. Please contact us with any address changes or other corrections to ensure accuracy in the database. If an address is incorrect the Post Office will not deliver under their revised policies and the mail piece will be returned and we will be charged a fee. Please notify us immediately of any changes to avoid extra postal fees. As Technical Director I also invite your input and assistance in improving our organization's operations, especially in maintaining our website. Thank you.

Dave Arntsen

Lupus and Allied Diseases Association is proud to be a member of the

- National Coalition of Autoimmune Patient Groups
- Lupus Research Institute National Coalition
- NIAMS Coalition
- Lupus Agencies of New York State
- NIAMS Lupus Federal Working Group
- Coalition for Accessible Treatments—CAT
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- ◆ Alliance for Safe Biologic Medicines—ASBM
- Patient Access for Florida
- Florida Patient Stability Coalition
- MAPRx Coalition



Beanie Bears \$10 each

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DISCLAIMER

May WLD Victorian Tea

Memorials, Tributes & Donations

Awareness & Advocacy Photos

It is the policy of the Lupus and Allied Diseases Association, Inc. to publish articles on Lupus and related diseases that have been written by physicians, nurses, and other healthcare providers and medical professionals. The opinions and statements expressed by the authors or contributors to this publication do not necessarily reflect the opinions or positions of the Lupus Communiqué, or the Lupus and Allied Diseases Association, Inc.

The material published herein is provided for informational purposes only and does not imply endorsement of any specific treatment, product, clinical trial, company or organization. We oppose self-diagnosis and self-treatment and urge readers to discuss any concerns they may have regarding diagnosis and treatment with their physicians. All rights reserved. No material in this issue may be copied or published without the express written consent of the Lupus and Allied Diseases Association, Inc. Thank you.

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President's Message—

As I sit here pondering over the most appropriate words to use to convey my annual message to you, I think back to the first one I wrote years ago. It was 1990, David and I had just gotten married and I was the newly-elected President of the LFA, Marguerite Curri Chapter. I had big shoes to fill, following in the footsteps of Peter & Dorothy Curri, Angela "Aya" Lo Conti, and Mary Lou Mazza. My goal was to convey my gratitude to the organization and its members for supporting me during the difficult early years after diagnosis and for encouraging me to be a leader. I was very young and inexperienced back then, yet passionately believed in the promise of research to develop better medications and cures. Sharing that sentiment and providing much-needed hope for an uncertain future to others was cathartic for me in my lupus journey and helped to launch my advocacy career.

While others promoted cures, I questioned why lupus research wasn't also directed at improving patient quality of life through the discovery of safer, more effective treatments? Afterall, most of us were being treated with corticosteroids and/or chemotherapy drugs and suffering from both the disease and medication side effects. In my naïveté I couldn't fathom how researchers would be able to find cures without first knowing what causes lupus. I was captivated by the research community, voraciously reading publications and pestering the presenters at meetings. Their expertise, brilliance and findings provided hope and inspiration for a better tomorrow and motivated me to face each day, even during the difficult times. It is that inability to accept the status quo, to perpetually challenge the norm, and to think outside the box that makes for bold research pioneers and formidable advocates.

2015 was another record breaking year for the annual Golf Classic with net proceeds of \$59,000 thanks to our wonderful supporters remaining steadfast and generous far beyond our expectations. On a much broader scale it has been a remarkable year of progress for all in the lupus and autoimmune communities. Innovative translational research and development initiatives that include collaborative stakeholder partnerships are taking place that give us hope that safer, more effective therapies and cures are just around the corner. The past year has been a whirlwind of activity for LADA both on the state and federal level. We joined several powerful advocacy coalitions, provided public comments regarding important regulatory policies, legislative issues and research initiatives, participated in the *CDC Public Health Agenda for Lupus* and the *NIH Action Plan for Lupus Research*, collaborated on the Ethics of Step Therapy Project, and partnered on the Lupus Patient-Focused Drug Development Initiative. We also presented at several advocacy summits and boldly inserted ourselves into the research and development communities whenever possible to make sure a patient voice was included and heard. "The patient perspective is powerful, passionate, persistent, persuasive and non-proprietary."

Most importantly, we expanded our collaborative efforts with other healthcare stakeholders to promote patient-centered care and continue our commitment to improving access to all therapies for all Americans and driving research and development forward with the patient as an equal stakeholder. Now more than ever, as we usher in an era of personalized health care and initiatives like 21st Century Cures, Healthier Americans and Precision Medicine move forward, it is evident that reformation of unethical and egregious insurance practices is long overdue. These payer protocols must be revolutionized to keep pace with biomedical innovation and to ensure ethical responsibilities are being met.

We are grateful for the accomplishments of the past year and continuously amazed by the dedication of all in the advocacy and research communities. It is only through our united efforts that we can move forward and succeed in the battle against lupus and other life-diminishing diseases. We at The Lupus and Allied Diseases Association are proud to play a small, but active role and honored to represent you during these exciting times. We have high expectations for a year filled with tremendous promise and progress into the diagnosis, treatment, and research of diseases of unmet need like Lupus. We are extremely thankful for your ongoing support; afterall, Lupus ends with US!

Hope for a Beautiful Spring and Be Well—Kathleen

NIH ACTION PLAN FOR LUPUS RESEARCH

In response to a request from the Congressional Lupus Caucus, the National Institutes of Health (NIH) has released an Action Plan for Lupus Research. This report was a collaborative effort, led by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) on behalf of the NIH. It represents a synthesis of internal and external input on promising future research directions to improve the lives of people with lupus.

In 2005, the House Appropriations Committee directed the NIH to develop a plan to guide the nation's investment in lupus research. In response, The Future Directions of Lupus Research was released in 2007. In July 2014, the Congressional Lupus Caucus requested that NIAMS, as the lead agency of the Lupus Federal Working Group, develop a new coordinated action plan for lupus research. "We have made great strides in our understanding of lupus and its treatment since the publication of the 2007 report," noted NIAMS Director Stephen I. Katz, M.D., Ph.D. "Yet, much work remains to be done."

The plan was developed collaboratively among the NIH Institutes and Centers with an interest and investment in lupus research, with extensive input from the broader community of researchers, health care providers, patients, and the Lupus Federal Working Group. Kathleen Arntsen, Dr. Betty Diamond and Dr. Marc Chevrier gave input on behalf of Lupus and Allied Diseases Association during the process. The plan highlights many opportunities to increase our understanding of lupus at the molecular, individual, and population levels, which ultimately should lead to safer and more effective treatments and, eventually, curative strategies. In addition, it will help to inform priority-setting processes among all lupus-related organizations — federal, private, and non-profit — and serve as a guide for lupus investigators.

To see a copy of the plan and article on the recent Congressional Briefing click on the links below.

http://www.niams.nih.gov/About Us/Mission and Purpose/action plan lupus.asp

http://lupusnewstoday.com/2016/03/21/for-charles-nih-action-plan-for-lupus-research-presented-at-congressional-briefing/

PUBLIC HEALTH AGENDA FOR LUPUS

The first-ever national roadmap to improve treatment and care for people with lupus was unveiled during a briefing on Capitol Hill on October 29. Lupus and Allied Diseases Association President and CEO Kathleen Arntsen and Vice President Sandi Frear attended the launching. The National Public Health Agenda for Lupus identifies public health priorities, strategies and recommendations that are relevant and complementary to efforts in lupus biomedical research and clinical care and serves as a model of a comprehensive approach to lupus care and treatment.

The Agenda was developed by the Lupus Foundation of America (LFA) and the National Association of Chronic Disease Directors (NACDD) in collaboration with leading lupus and public health experts and people living with lupus. Kathleen Arntsen sat on the Steering Committee and contributed to the development of the plan. The effort was made possible through funding from the United States Centers for Disease Control and Prevention (CDC).

To see a copy of the plan click on the link below.

http://www.lupus.org/pages/first-ever-national-public-health-agenda-for-lupus-full-report

Lupus Study Shows Precision Medicine's Potential To Define The Genetics of Autoimmune Disease

DALLAS – March 18, 2016 – Demonstrating the potential of precision medicine, an international study based at UT Southwestern Medical Center used next-generation DNA sequencing technology to identify more than 1,000 gene variants that affect susceptibility to systemic lupus erythematosus (SLE).

Precision medicine is an emerging field that aims to deliver highly personalized health care by understanding how individual differences in genetics, environment, and lifestyle impact health and disease.

SLE, commonly called lupus, is a serious, potentially fatal autoimmune disease that the National Institutes of Health reports affects nine times more women than men, and is more likely to strike young African-American, Hispanic, Asian, and Native American women. The disease often begins between the ages of 15 and 44.

"SLE starts when the immune system attacks multiple organ systems in the body, which can result in a complex array of symptoms that are difficult to manage clinically and can lead to organ damage," said Dr. Edward Wakeland, Chair of Immunology at UT Southwestern and co-senior author of the study posted online recently in the journal eLife. "Our findings support the potential of precision medicine to provide clinically relevant information about genetic susceptibility that may ultimately improve diagnosis and treatment."

The study also may have implications for other systemic autoimmune diseases, a category of diseases that affect multiple body systems and includes Type 1 diabetes, rheumatoid arthritis, and multiple sclerosis, he said.

Dr. Wakeland and colleagues sequenced millions of DNA base pairs from more than 1,700 people, which allowed precise identification of the genetic variations contributing to SLE, he said. Specifically, the researchers identified 1,206 DNA variations located in 16 different regions of the human genome associated with increased susceptibility to SLE. They then showed that almost all of them (1,199) modify the level of expression of specific molecules that regulate immune responses, he said.

In addition, the two-year study identified many of the specific regulatory variations that were changed in SLE patients and demonstrated that accurately identifying such so-called causal variants increased the accuracy of the genetic association of individual SLE risk genes with susceptibility to SLE.

"Prior to our study, such a comprehensive sequence analysis had not been done and little was known about the exact genetic variations that modify the functions of the genes that cause SLE," added Dr. Wakeland, who holds the Edwin L. Cox Distinguished Chair in Immunology and Genetics.

The scientists began their comprehensive sequence analysis using the DNA samples of 1,349 American Europeans (773 with SLE disease and 576 without) from sample collections at UT Southwestern, the University of Southern California, UCLA, Oklahoma Medical Research Foundation, and the Université Catholique de Louvain in Belgium.

They then determined the precise DNA sequences at SLE-associated genetic regions scattered throughout the genome. They found that SLE risk is associated with specific clusters of DNA variations, commonly called haplotypes, and that some haplotypes increased the risk for SLE while others provided protection from SLE.

After identifying the sets of DNA variants that increased SLE susceptibility in Caucasians, they used multiple public databases, including the international 1000 Genomes Project (2,504 genomic samples from the global human population) to determine whether these haplotypes also were found in South American, South Asian, African, and East Asian populations.

They discovered that the variants and haplotypes were distributed across subpopulations worldwide. Their findings indicate that many common haplotypes in the immune system are shared at different frequencies throughout the global population, suggesting that these variations in the immune system have ancient origins and persist in populations for long periods, Dr. Wakeland said.

"We thank the many SLE patients and control participants whose sample contributions were essential for these studies," the researchers wrote.

(Lupus Study continued)

Dr. Wakeland and colleagues plan to continue the research by obtaining more DNA samples and expanding their analysis to additional SLE risk genes with the goal of obtaining a data set that can be used to predict an individual's unique risk of SLE, as well as the likelihood of benefiting from specific treatments.

"It is feasible that this same type of genetic analysis will allow the clustering of SLE patients into specific groups, based on their genetic predispositions, which would improve clinical management and potentially allow the development of more targeted therapies," Dr. Wakeland said.

Earlier this month, UT Southwestern announced that Dr. Wakeland, whose laboratory has long served as the institution's Genomics and Microarray Core Facility, will be leading a large DNA-sequencing initiative to address important clinical challenges. The new clinical sequencing facility, in collaboration with the Department of Pathology, will provide panel sequencing for cancer and other diagnoses, and eventually expand to whole-exome and whole-genome sequence analysis for a variety of patients. The laboratory will be established in the BioCenter on the East Campus. To commit full effort to this initiative, Dr. Wakeland will step down as Chair of Immunology, but will remain in this role until his successor is named.

"This clinical sequencing core facility will generate laboratory data to be used for the evaluation of patient tumors. I hope we will someday expand to genotyping patients to identify potential susceptibility to autoimmune disease and many other conditions as the field of precision medicine develops," Dr. Wakeland said.

Co-lead authors of the eLife study from UT Southwestern were Dr. Prithvi Raj, Instructor of Immunology, and Dr. Ekta Rai, a former postdoctoral fellow in the Wakeland lab. Other contributing UTSW authors, all from Immunology, included Dr. Ran Song, postdoctoral researcher; Dr. Shaheen Khan, Instructor; Benjamin Wakeland, database analyst; Kasthuribai Viswanathan and Carlos Arana, computational biologists; Chaoying Liang, laboratory manager; Bo Zhang, senior research associate; Ferdicia Carr-Johnson; former lab manager; and Dr. Igor Dozmorov, Dr. Chandrashekhar Pasare, and Dr. Quan-Zhen Li, Associate Professors. Dr. Pasare holds the J. Wayne Streilein, M.D. Professorship in Immunology and is a Louise W. Kahn Scholar in Biomedical Research.

Additional UTSW co-authors include Dr. Christine Garcia, Associate Professor of Internal Medicine and in the Eugene McDermott Center for Human Growth and Development; Dr. Carol Wise, Professor of Orthopaedic Surgery and in the McDermott Center; and Dr. David Karp, Chief of Rheumatic Diseases and Professor of Internal Medicine. Dr. Garcia holds the Kern and Marnie Wildenthal President's Research Council Professorship in Medical Science, while Dr. Karp holds the Fredye Factor Chair in Rheumatoid Arthritis Research, and the Harold C. Simmons Chair in Arthritis Research.

Co-senior author was Dr. Patrick Gaffney of the Oklahoma Medical Research Foundation. Others contributors were from Yale School of Medicine, Oklahoma Medical Research Foundation; Université Catholique de Louvain; Penn State College of Medicine; Cincinnati Children's Hospital Medical Center and Cincinnati VA Medical Center; University of Southern California; and UCLA.

This study was supported by the National Institutes of Health, the Alliance for Lupus Research, and the Walter M. and Helen D. Bader Center for Research on Arthritis and Autoimmune Diseases.

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About University of Texas Southwestern Medical Center

UT Southwestern, one of the premier academic medical centers in the nation, integrates pioneering biomedical research with exceptional clinical care and education. The institution's faculty includes many distinguished members, including six who have been awarded Nobel Prizes since 1985. The faculty of almost 2,800 is responsible for groundbreaking medical advances and is committed to translating science-driven research quickly to new clinical treatments. UT Southwestern physicians provide medical care in about 80 specialties to more than 100,000 hospitalized patients and oversee approximately 2.2 million outpatient visits a year.

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15th ANNUAL LUPUS CHARITY GOLF CLASSIC

























2015 GOLF CLASSIC WINNERS







The 15th Annual Lupus Charity Golf Classic was held on August 20th, 2015 -- a beautiful day for record-breaking at Shenendoah Golf Club at Turning Stone Resort in Verona, NY. More than \$59,000 net and a new fundraising record was set to support our program services. Thank you to all of the golfers, sponsors, volunteers, and supporters who made the event possible.

Closest to the Pin













Longest Drive









Kaluhyat Golf Course at Turning Stone Resort

Thursday, August 25, 2016

Proceeds Benefit:

Lupus and Allied Diseases Association, Inc.

A Premier Charity Golf Tournament

Registration - 11:30 AM

Shotgun Start - 1:00 PM

Tournament Format: Captain & Crew 4-Person Scramble

LUNCH - GOLF - AWARDS BANQUET - PRIZES

Accepting Registration for:

Teams - Pairs - Individual Golfers Men, Women, Senior and Co-Ed Categories

Early Registration by July 25th \$175 per golfer Registration after July 25th \$200 per golfer

Sponsorship Opportunities Available



Help to Make a Difference for those Affected by Lupus and Allied Diseases while enjoying a great round of golf

Honorary Chairman - Donald A. Raddatz, MD

Bassett Healthcare Rheumatologist

For more information on Registration, Sponsorships or Prize Donations Call 315-829-4272 or e-mail lupusinnovators@aol.com or visit our website www.nolupus.org

LUPUS ALLIED DISEASES Association, Inc.

SIXTEENTH ANNUAL LUPUS CHARITY GOLF CLASSIC

AUGUST 25, 2016





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*All foursomes include 18 holes of golf w/cart, lunch, and dinner for four. For additional information call 315-829-4272 or 1-866-2-LUPUS-4 or E-mail LupusInnovators@aol.com

Please make checks payable to: Lupus and Allied Diseases Association PO Box 170 Verona, NY 13478

An Invitation to Celebrate World Lupus Day

WHAT: Victorian Tea

WHERE: Your Home

WHEN: May 10, 2016

Recipe for a successful tea party:

1. Dust off the stove

- 2. Find the teapot (a mug & microwave will also work)
- 3. Cookies Optional
- 4. Turn off all phones and electronic devices
- 5. Kick off your shoes
- 6. Play your favorite music
- 7. Write out your donation check

Please consider supporting the our cause this Spring by participating in our World Lupus Day Victorian Tea. Proceeds from this non-event will be used to fund our Organization's Program Services:

Newsletter Printing & Postage Lupus Awareness, Advocacy and Public Education Programs Continued Training to update our leaders on current information Distribution of lupus materials for awareness events Telephone hotline and website

Please make checks payable to:

Lupus and Allied Diseases Association PO Box 170 Verona, New York 13478



Thank you for your Consideration and Support!!!

The Lupus and Allied Diseases Association, Inc. is a tax-exempt charitable organization eligible to receive tax-deductible contributions under IRS Code Section 501(c)(3). Our federal tax identification number is 16-1083229 and a copy of our latest annual report may be obtained upon request from us or The NYS Attorney General's Charities Bureau at 120 Broadway, NY, NY 10271. For more information on our event please contact us by phone at 315-829-4272 or e-mail lupusinnovators@aol.com.

Memorials, Tributes, and Donations

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Wellington Walseman-Bob & Cathy Walseman

Douglas Kerr-Bob & Cathy Walseman

James McCarthy-Larry & Karen Woolshlager

> Eleanore Iglesias-Lisabeth Iglesias

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> Joseph Jupin-Victoria Jupin

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> Mary Alice Mitchell-Jane Williams

James E. Mitchell-Jane Williams

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> Daniel Iglesias-David & Kathleen Arntsen

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Tributes

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Monica & Rocco Falitico-Virginia Merola

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James Mitchell's Birthday-David & Kathleen Arntsen

> Cathy Walseman-**Bob** Walseman Isabel Woolshlager

James & Patricia Mitchell for Christmas-David & Kathleen Arntsen

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LUPUS & AUTOIMMUNE AWARENESS AND ADVOCACY IN ACTION



























