LUPUS AWARENESS LICENSE PLATES

Lupus Awareness License Plates are now available to order in New York State from the NYS DMV and the monies raised from the purchase of the special plates will go to the lupus research and education fund. The lupus awareness plate project was initiated by New York State Senator Kevin Parker and Assemblymember Crystal Peoples-Stokes through their sponsored legislation that was passed by the state legislature and became law in 2017.

The goal of the awareness plates is to promote much-needed lupus awareness and education throughout the state, while monies received into the lupus research and education fund will be used to finance research to hopefully improve the quality of life for New York residents living with lupus. The awareness plate initiative is a result of the collective efforts of the Lupus Agencies of New York State which include: Lupus Alliance of Upstate New York, Lupus and Allied Diseases Association, Lupus Foundation of America and Lupus Research Alliance and the countless New Yorkers who advocated for this bill along with other lupus legislation.

The Lupus Agencies of New York State have been coming to the New York State Capitol Building for 17 years to promote lupus awareness during the month of May in the Senate and Assembly chambers. The organizations extend gratitude to Senator Parker and Assemblymember Peoples-Stokes and the members of the Senate and Assembly for supporting and passing the legislation and Governor Cuomo for signing it into law. The plates can be ordered by telephone at (518) 402-4838 or online through the link https://dmv.ny.gov/plates/lupus-awareness
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 while supporting our cause. If you belong to a Service or Fraternal organization, or participate in a workplace-giving program such as: SEFA, UNITED WAY, IBM, GE 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 address changes or other corrections to ensure database accuracy. The Post Office will no longer deliver to an incorrect address so the mail piece will be returned. 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

PRIVACY POLICY

Lupus and Allied Diseases Association, Inc. has the utmost respect for the privacy of our donors.

- Lupus and Allied Diseases Association will not sell, share, or trade a donor’s personal information with other organizations, except where disclosure is required by law;
- Lupus and Allied Diseases Association will not send donor mailings on behalf of other organizations;
- Lupus and Allied Diseases Association does list all donor’s names in The Lupus Communiqué, its annual newsletter, unless the donor opts out by providing a written or verbal request for their donation to remain anonymous.

Please contact Dave at 315-829-4272 or by e-mail at Info@LADAinc.org if you have questions regarding our privacy policy.
TABLE OF CONTENTS

Lupus Awareness in NY 1
Newsletter Information 2
Organization Information 3
President’s Message 4-5
2019 and 2020 Golf Classic 6-7
Education Program 8
Advocacy Programs 9-10
Memorials, Tributes & Donations 11-13
ACR Lupus Exhibit 14
Lupus Research Support 15
Lupus Warriors Photo Montage 16

DISCLAIMER

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 Communiciqué, 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.

BOARD OF DIRECTORS
President/CEO
Kathleen A. Arntsen
1st Vice President
Sandra M. Frear
2nd Vice President
Jacqueline L. Taylor
Treasurer
Philip A. Teague
Secretary
David L. Arntsen
Members
Lisabeth S. Iglesias
Estela Mata-Carcamo
Juana Mata
Jane M. Porter
Brian J. Vogel
Lori A. Vogel
Anna M. Zablotowicz
Honorary
Medical Advisory Board
Marwan Al-Haddad, MD
Dermatologist
Atul Butala, MD
Hematologist
Gregory Cummings, MD
Neurologist
Victoria Laucello, MSW
Psychologist
Martin Morell, MD
Rheumatologist
Donald Raddatz, MD
Rheumatologist
Raquel Rosen, MD
Nephrologist
Helen Sarandrea, PT
Physical Therapist
Julia Simard, ScD
Epidemiologist

The Lupus Communiciqué
Is published once a year by
Lupus and Allied Diseases Association, Inc.
PO Box 170 Verona, NY 13478
Phone: 315-829-4272 or 1-866-258-7874
Fax: 315-829-4272
E-mail: Info@LADAinc.org
www.LADAinc.org
As Lupus and Allied Diseases Association (LADA) enters our 42nd year of existence as an all-volunteer, passion-driven charity led by individuals with lupus and their loved ones, I am filled with amazement and draw inspiration from the millions of Americans struggling to manage their lupus or other immunocompromising conditions in the face of Covid-19 and additional adversities with tremendous grace, dignity, and courage. Despite dealing with a global pandemic, economic crisis of massive proportions, systemic racism, travel restrictions, social distancing, mask requirements, contradictory news reporting, hydroxychloroquine hijacking, school and work videoconferencing, telehealth appointments, drug scarcities, food and basic essentials shortages, and an overburdened and inequitable healthcare system; people with lupus and allied diseases and their loved ones, healthcare providers, and patient advocacy organizations have demonstrated remarkable adaptability and resilience this year.

This is not surprising since dealing with a disease like lupus teaches you very early on about unpredictability, and how to be patient, avoid people with germs, wear masks in public, stock up on essentials, and rely on your medical treatment team and credible evidence-based scientific resources for information. You come to understand pain, limitations, and loss. This real world training comes in handy during a pandemic.

Our lupus advocacy community began over 50 years ago at kitchen tables and in church basements where the newly diagnosed and their families came together to find answers, and provide comfort and support for each other at a time when little information existed on this confounding disease. These small groups grew into a grassroots effort that eventually became larger organizations with chapters, affiliates and virtual support systems that now post, tweet, chat, snap and like with the touch of a finger. For too many decades our community has witnessed the devastation of this relentless disease, shed countless tears, and spent hours praying and grieving in hospitals, places of worship, and burial grounds. Advancing lupus and autoimmune drug development and research has become a motivator for individuals with lupus and their loved ones who have fought to not only manage the disease but to also make their voices heard along the way and is a priority for our community.

Although we were not able to attend conferences and hold in-person education and advocacy events from March 2020 on, we still achieved another outstanding year of growth here at LADA, due in part to our fiscal year beginning on October 1, 2019. We were also fortunate to be able to still hold our 2020 Golf Classic in August with appropriate safety modifications. We are thankful that we continue to receive outstanding support from people with lupus and their families, friends, unions, healthcare providers, corporations, and employers who understand that lupus does not just affect individuals but impacts everyone close to us. We are also extremely blessed to have many friends in the advocacy community who not only work alongside us on access and research initiatives but support us as well. Our many volunteers and supporters continue to amaze us with their generosity and kindness, far surpassing our expectations.

In the past 17 months we continued to promote patient-centered healthcare, patient-focused research and empowerment programs for individuals impacted by lupus and other diseases of unmet need. We worked tirelessly to ensure that the patient perspective was included and recognized as an equal stakeholder in the healthcare, public policy and regulatory arenas and across the research continuum. We fought to improve patient access to care and quality of life by fostering collaboration among stakeholders, promoting unity in the community and wielding the patient voice as a catalyst to advance innovative advocacy, education, awareness and biomedical research initiatives. We also continued to promote lupus awareness to improve disease recognition, patient outcomes and quality of life and supported lupus and autoimmune research efforts to identify causes, advance better diagnostics, and discover superior treatments, and cures.
LADA joined global efforts including the World Lupus Federation (WLF), World Patients Alliance (WPA), International Association of Patient Organizations (IAPO), and the Covid Advocacy Exchange (CAE) to promote patient-centered care and share resources worldwide. We continue to: fight for appropriate care and treatments during the COVID-19 pandemic to preserve access to hydroxychloroquine and chloroquine, allow home care coverage for infusible and injectable therapies, promote vaccine education initiatives, and endorse telehealth options to support treatment adherence; engage with the Institute for Clinical and Economic Research (ICER) to provide our unique viewpoint during their review of potential lupus and lupus nephritis drugs; participate as a Global Advisory Committee Member of the Addressing Lupus Pillars for Health Advancement (ALPHA) Project; and we will continue to support lupus warriors in their quest to share their journeys and viewpoints in forums such as the ACR’s Patient Perspectives Poster Initiative. (I am honored to share with you that all three of LADA’s sponsored posters were chosen for presentation at this year’s ACR Meeting in November, we had two last year in 2019.) We are also developing a Diversity, Equity and Inclusion Plan to evaluate and vanquish health and social inequities. Our various programs can be found in the newsletter.

Last May when I wrote my previous President’s Message, I could never have imagined that 2020 would be a year filled with life altering events on a global, national, state and personal level. Although I am moving slowly forward following the recent losses of my Mother, Father and Mother-in-law, I am cautiously optimistic about the future and inspired by our ability to come together as a community to face our challenges, overcome adversities, and construct a healthier, more empathetic, equitable and robust culture. Thank you for your support during this difficult time. We are here for you and your loved ones as you continue on your lupus and allied diseases journey and are grateful for your ongoing involvement and support. Afterall, Lupus ends with Us!

Stay Safe and Be Well—Kathleen

LADA’s Statement on Racism and Inequality

As our nation continues to experience turmoil and uncertainty during these challenging times from both the COVID-19 pandemic and its effect on the economy, many Americans now struggle to address longstanding systemic racism and inequality with the goal of impacting meaningful change.

The Lupus and Allied Diseases Association is extremely disheartened by and strongly opposed to acts of discrimination, injustice, racism, and violence and we stand with Black, Indigenous and People of Color and LGBTQ communities and others who desire a more empathetic, respectful, tolerant and just society.

We are dedicated to addressing and overcoming social inequities and health disparities through effective advocacy, especially since both lupus and COVID-19 disproportionately impact communities of color.
The 19th Annual Lupus Charity Golf Classic was held on August 22nd, 2019 at Shenendoah Golf Club at Turning Stone Resort in Verona, NY. More than $110,000 gross and $92,000 net was raised to support our awareness, education, advocacy, and research program services. Thank you to the many golfers, sponsors, prize donors, volunteers, and supporters who made the event a success.
The 20th Annual Lupus Charity Golf Classic was held on August 20, 2020 at Shenendoah Golf Club at Turning Stone Resort in Verona, NY with safety precautions in place that included mandatory masks, social distancing, plated meals and less participants. More than $105,000 gross and $89,000 net was raised. Thank you to all of the golfers, sponsors, volunteers, and supporters who believed the event was still possible.
Although we were sidelined for 2020, we are excited to announce that due to the success of the 2019 education programs, Lupus and Allied Diseases Association will be taking our Enhancing Lives by Empowering the Lupus Community Education Symposium and Luncheon on the road again in 2021. We are partnering with The Michigan Lupus Foundation in Detroit, MI on Saturday, April 17, 2021; LupusChat in Brooklyn, New York on Saturday, May 1, 2021; and Lupus Foundation New England in Boston, MA on Saturday, October 2, 2021. The program is open to people with lupus and other autoimmune conditions, their loved ones, care partners, medical students, patient advocates, sponsors, and others interested in the topics. The event and luncheon are FREE but everyone must register to attend.

To learn more about the program or to register please visit https://bit.ly/LADARoadShow

We sincerely appreciate the generous support of our 2020-21 Education Symposium Sponsors, Platinum Luncheon Level—Aurinia Pharmaceuticals, BIOGEN/UCB, Kezar Life Sciences, and GlaxoSmithKline (GSK); and Gold Program Level—AbbVie, AstraZeneca, Bristol Myers Squibb, and Janssen/Johnson & Johnson Health Care Systems, Inc.

Pictured above are speakers Brian Nyquist from NICA, Melaca Cannella from Sjogrens Lupus Hawaii, and Kathleen and David Arntsen from LADA at the Education Symposium in Honolulu, HI in March 2019; above right are hosts Kelli Roseta and Christine Von Raesfeld from More Than Lupus, Kathleen Arntsen from LADA, Estela and Juana Mata from Looms for Lupus, and David Arntsen from LADA at the April 2019 Education Symposium in San Francisco, CA; pictured right are speakers Brian Nyquist from NICA, Kathleen and David Arntsen from LADA, and clinical researcher Dr. Susan Boackle from the University of Colorado School of Medicine at the October 2019 Education Symposium in Littleton, CO co-hosted by the Lupus Foundation of Colorado.
Make Your Voices Heard Initiative

LADA launched a novel patient advocacy program in late 2019, Make Your Voices Heard, an initiative designed to educate and empower additional individuals with lupus and autoimmune diseases and their loved ones to learn how to effectively elevate their voices to advocate on state and federal healthcare access, regulatory, research and public policy issues that affect their lives. This program focuses on the importance of people directly impacted by diseases becoming actively engaged in the advocacy process by turning their emotion into motion and using their voice as a catalyst to influence positive change.

One of the project’s goals is to educate and train people with lupus and other autoimmune conditions and their care partners to learn about the nation’s regulatory proceedings and witness FDA advisory committee meetings in person in order to obtain a better understanding of the stages of the U.S. drug and device research and development process.

LADA Board Members and patient advocates Sandi Frear and Lisabeth Iglesias accompanied President & CEO Kathleen Arntsen as she shared her patient perspective on living with complex autoimmune conditions including Grave’s Disease, at the U.S. Food and Drug Administration (FDA) Dermatologic and Ophthalmic Drugs Advisory Committee (DODAC) on Friday, December 13, 2019 regarding a new Biologics License Application (BLA) to treat thyroid eye disease (TED). The biologic drug teprotumumab, is a fully human monoclonal antibody, IGF-1R inhibitor, and the first potential treatment of active thyroid eye disease; a debilitating, life-altering and life-diminishing disease of urgent unmet need.

The highlight of the meeting was being present at the conclusion to witness the advisory committee’s actual vote recommending whether to approve the drug or not. The committee voted unanimously to approve the drug, but the process did not end there as the FDA then reviews the committee’s recommendation along with the research data and findings and all written and oral comments and then makes a determination after the meeting. The drug was approved in January 2020 and is administered by IV infusion.

LADA would like to thank Amgen and AdvaMed for their support of this important initiative.
LADA is continuing Enhancing Lives By Amplifying the Patient Voice, our patient-focused education initiative started in January 2019. The objective of this program is to provide an opportunity for people with lupus and loved ones to attend key advocacy and scientific meetings in order to learn, network, and share their unique patient viewpoints while informing other attendees and sharing their experiences within their communities. It is our hope that including multiple patient voices at these forums will offer valuable insights, and inspire dialogue, synergy and positive action within the lupus, autoimmune and rheumatology communities. We gratefully acknowledge the generous support of our Patient Voice Program Sponsors Mallinckrodt Pharmaceuticals, BIO, Celgene and Genentech.

LADA Patient Advocates at the LFA’s Annual Advocacy Summit in March 2019 in Washington, DC pictured with Catherine Jackson, RN, BSN, MPH, Director of Advocacy at Mallinckrodt Pharmaceuticals (center).

Senator Diane Savino (front row 2nd from left) and Senator Kevin Parker (front row 2nd from right) with NY Lupus Advocates and the legislative awareness resolution in the capitol building at the 2019 May Lupus Awareness Event in Albany, NY.

LADA Patient Advocates at the Annual American College of Rheumatology (ACR) Meeting in Atlanta, GA in November 2019 where they were able to interact with attendees and help to man the Lupus Community Exhibit.

LADA Board Members and Patient Advocates Estela Mata (far left), Kathleen Arntsen (center back), and Juana Mata (far right) with other meeting attendees at the Lupus 21st Century Conference in Bethesda, MD in October 2019.
Memorials, Tributes, and Donations

Memorials
In Loving Memory of…

Marian J. Arntsen-
Kristi Lengyel, Dan & Lois Rumfelt
David & Kathleen Arntsen

Patricia Ann Mitchell-
Bill & Sandi Frear, Helen Cassin
Larry & Kathy Scharf
Michael & Victoria Laucello
Frank, Stephanie, Samantha, Valerie
and Frankie Darwak
Dave & Carol Way, Phil & Kathy Teague
Tony & Anna Maria Maritato
William & Julia Mitchell, Jill Anne Smith
Bob & Cathy Walseman
Edward & Judy Bentley, Tony & Jackie DiLucci
Lupus Society of Illinois, Anne Zablotowicz
UCB, Inc., Kristi Lengyel
Joseph, Lori & Brian Vogel
The Chenango Canal Association
Pfizer Foundation, Marc & Diane Chevrier

James Edward Mitchell, Jr.-
William & Julia Mitchell
Susan Keller
Phil & Kathy Teague
Dave & Carol Way
Michael & Patricia Mitchell
Randy & Diane Dymond
Edward & Judy Bentley
Dick & Helen Lenart
Tony & Jackie DiLucci
Frank, Stephanie, Samantha, Valerie
and Frankie Darwak
Tony & Anna Maria Maritato
Dan & Lois Rumfelt
Fran & Diane VanSlyke
Kristi Lengyel
Joseph, Lori & Brian Vogel
Bob & Cathy Walseman
Shawn Keoghhan, BMS

Rocco Falitico-
Marlyn Ferrare, Theresa Mecca
Kimberly Augustine, Andrea Radesi
David & Kathleen Arntsen
Vince, Carol, Lynnea & Joe Ivsan
Sidney & Lucille Porter
Mr. & Mrs. Joseph Rosato
Carrie Kindler & Victor Choo
Graham Manufacturing

Tributes
In Loving Honor of…

Cathy Walseman-
Bob Walseman & Isabel Woolshlager
Jeffrey & Susan Virkler & Family

Jackie Taylor-
UFCW District Union Local ONE

Sandi Frear’s Birthday-
Friends & Family

Brian Vogel-
Joseph & Lori Vogel, Ron & Sue Durgan
Wayne Towne, Mike Phillips, Steve Mack, Andy Trela

Maryrose Bullock-
Dale Bullock, Tom Francisco, Mike Simonds, Mike Hinkley, BΣϕ Alpha Iota Oneonta Chapter

Kathleen Arntsen-
James & Patricia Mitchell, Dan & Lisa Mitchell

All Lupus Warriors-
Juana & Estela Mata

World Lupus Day Tea

David & Kathleen Arntsen
Monica Falitico
James & Patricia Mitchell
Tom & Jackie Taylor
Jack & Marcia Flint & Family
in honor of Cathy Walseman
Bill & Sandi Frear
Phil & Kathy Teague
Lisabeth Iglesias

Victoria Jupin in loving memory of Frank Jupin
Jane Porter
Helen Cassin
Samantha Darwak
Laurie Domanico
Estela Mata
Juana Mata

Joseph & Lori Vogel
Brian Vogel
Ron & Sue Durgan
Lynn Houseknecht

Anne Zablotowicz in honor of her Lupus Family
Anne Zablotowicz in memory of Special Moms
Fran Iglesias-Tosti
Memorials, Tributes, and Donations

Memorials
In Loving Memory of…

Charles & Bernie Carter-
Bob & Cathy Walseman, Isabel Woolshlager
Jeffrey & Susan Virkler & Family
Larry & Karen Woolshlager & Family

Wellington & Doris Walseman,
Douglas Kerr-
Bob & Cathy Walseman

Marguerite Curri,
Peter & Dorothy Curri
Angela “Aya” Lo Conti, Dan Lo Conti
Michael P. Jones, Elizabeth Jones
Amy Bryant Mowers, Rosemary Franklin-
David & Kathleen Arntsen

The Reverend S. Kenneth Arntsen,
Linda Arntsen & Donald Arntsen-
David & Kathleen Arntsen
Marian J. Arntsen

Richard, Penny & Bobby Cassin-
Helen E. Cassin
Barbara M. & Robert E. Porter-
Bill & Sandi Frear & Jane Porter

John & Isabell Zeock-
Bill & Sandi Frear & Helen Cassin

James & Rose McCarthy
Anita Curtiss, Carol Honors,
Richie Hanlon, Tom McCabe, Sr.-
Larry & Karen Woolshlager & Family

Elwood Virkler-
Jeffrey & Susan Virkler & Family

Anita Russell-
David & Kathleen Arntsen

Annie Ravitz-
David & Kathleen Arntsen

Caroline Olsen-
Paul Olsen

Joseph Jupin-
Victoria Jupin

Memorials
In Loving Memory of…

Lorna E. Relf, Louis A. Relf
Richard Sam Relf
Elva Fox, Arthur A. Relf
John & Alberta Bagley
Emery & Alice Bagley-
David & Kathleen Arntsen

Shawna Lynn Mitchell
James E. Mitchell, Mary Alice Mitchell
Harold Leach, Pat Leach
William Leach, Catherine Leach
James E. Mitchell, Elizabeth Mitchell
Thomas P. Mitchell-
David & Kathleen Arntsen

Brooke N. Walseman-
Bob & Cathy Walseman, Isabel Woolshlager
Jeffrey & Susan Virkler & Family
Larry & Karen Woolshlager & Family
Jack & Marcia Flint & Family

Marie Eignor-
Bob & Cathy Walseman

Harold F. Woolshlager-
Bob & Cathy Walseman
Isabel Woolshlager
Jeffrey & Susan Virkler & Family
Larry & Karen Woolshlager & Family

George Williams, Thomas P. Mitchell,
Mary Alice Mitchell, James E. Mitchell-
Jane Williams

Betty C. Fitzgerald-
Bob & Cathy Walseman
Larry & Karen Woolshlager

Mary Margaret Della Posta-
David & Kathleen Arntsen

Louis Smith, Christine Marie Smith-
David & Kathleen Arntsen
Jill Anne Smith

Frances Eck-
David & Kathleen Arntsen
Memorials, Tributes, and Donations

Donations

CFC, SEFA, IBM, GE, Amex, Network4Good, United Health, Johnson & Johnson, and Pfizer
Employee Donor Plans
Pfizer, Inc., Pharmaceutical Research & Manufacturers of America (PhRMA)
Lupini Construction
PWR
Genentech
Amgen
Biotechnology Innovation Organization
AbbVie
NY State Correctional Officers & PBA
Carbone
ΒΣϕ Alpha Iota Oneonta Chapter
DTM²
James & Patricia Mitchell
Alliance for Safe Biologic Medicines
Exagen Diagnostics
Walmart Stores 1677 & 6038 & 2093 & 2285
David & Kathleen Arntsen
LifeMark Securities
Teague Accounting Xperts
Americu Credit Union, Commercial Drive Branch
Presto Print, LLC
Putnam Pest Control
Raquel Rosen, MD
Larry & Kathy Scharf
Arthritis Health Associates
Rick Deyulio
Gates Cole Associates
Tony & Anna Maria Maritato
MCORP—Dan & Lisa Mitchell
Bassett Healthcare Network
Margaret Ostergren
Janssen Pharmaceutical Companies of Johnson & Johnson
Arthritis Specialists
Monica Falitico
Joseph & Lori Vogel
George P. Coutros
Daniel & Lois Rumfelt
Brian Vogel
Ron & Sue Durgan
GlaxoSmithKline
Alliance for Gout Awareness
Lupus Foundation of America, Inc.
Rational PR, LLC
Brian Bush
Susan Keller
Marcia Laidlaw

Donations

Helen Sarandrea, Physical Therapy
Rick Widmeyer
Mark O’Rourke, Esq.
Marc & Diane Chevrier
Bob Walseman & Isabel Woolshlager
The Vandervort Group, LLC
Aurinia Pharma
UCB, Inc.
Lupus Research Alliance
Bristol-Myers Squibb
Astra Zeneca
Boehringer Ingelheim
Mallinckrodt Pharmaceuticals
Global Healthy Living Foundation
National Infusion Center Association
Donald Raddatz, MD
Kristi Lengyel
Takeda
Advamed
Beta Sigma Phi
Betty Servatius
Scott Brewster
Jane Porter
Bill and Sandi Frear
Helen Cassin
Samantha Darwak
Alliance for Patient Access
Coalition of State Rheumatology Organizations
Tony & Jackie DiLucci
Karl Lobo
Eli Lilly and Company
Horizon Therapeutics, USA, Inc.
Rheumatology Nurses Society
Sanguine Biosciences
Amanda Greene
Rebecca Geraghty
Patrick Geraghty
Lindsey Smith
Estela Mata
Juana Mata
Susan Foreman
EMD Serono
DxTerity Diagnostics
UFCW District Union Local ONE
Biogen
Marwan Al-Haddad, MD
Anne Zablotsowicz
Americu Credit Union, Oneida Branch
Matt Harutunian
Robert J. Ravitz
Nathan Fitzgerald
LADA sponsored the Lupus Exhibit at the American College of Rheumatology (ACR) Annual Scientific Meeting in Atlanta, GA in November 2019 to provide awareness and promote unity in the lupus community. The booth was manned by lupus patient advocates and staff representing lupus organizations from across the country. The meeting was attended by nearly 20,000 members of the Global Rheumatology Community and gives us the opportunity to share educational materials and resources with physicians and other healthcare professionals about lupus and the organizations. We appreciate the participation of the various groups: Lupus and Allied Diseases Association, Lupus Foundation of America, Lupus Research Alliance, Looms for Lupus, Lupus LA, Lupus Chat, and More Than Lupus and the efforts of our invaluable volunteers. We were thrilled that last year’s meeting had more patient representation than in previous years and were honored to sponsor Lupus Chat Executive Team Members Christele Felix, Tiffany Peterson and Carlene Harrison to participate in the Patient Perspectives Poster session. We will continue to provide various opportunities for people with lupus to be present and at the table to participate in the healthcare, regulatory, research and public policy arenas by supporting their attendance at key education and scientific meetings.

Pictured to the left are lupus advocates and staff representing various lupus organizations at the Lupus Community Exhibit at the 2019 ACR Annual Meeting. We debuted our redesigned Butterfly Backdrop created by LADA advocate and artist Mary-rose Bullock and her artist friends for our awareness events.
LADA's Record Breaking Research Support

For anyone struggling to live with lupus or to love someone with lupus, what motivates us to face another day is the hope that research advancements that will improve our lives lie just around the corner. Because of this, we believe wholeheartedly in investing in quality research here at the Lupus and Allied Diseases Association.

We are excited to announce that LADA supported two research grants totaling $220,000 in 2020 which made it a record breaking year for us in research support. We are honored to have now supported $1,084,000 in research funding overall to date since we began our research grant program in 1990. In April, we donated $100,000 to the Lupus Foundation of America for their promising pediatric research program and mesenchymal stem cell research program and $120,000 to the Lupus Research Alliance in September for their innovative lupus and autoimmune research program. Unfortunately, due to the pandemic, we were not able to present the checks in person this year.

Pictured above left are Lupus Research Alliance representatives Ian Kirkman, Jonathan Marks, Al Roy, and Dorey Neilinger receiving the LRA's annual research donation from LADA President & CEO Kathleen Arntsen and Secretary David Arntsen at the 2019 Golf Classic. Above right is Al Roy in the LRA Office in New York displaying our large check. Below left are Dr. Gary Gilkeson, from the Medical University of South Carolina (center) and LFA President & CEO Steve Gibson (right) at the 2019 LFA Advocacy Summit in Washington, DC receiving LADA’s donation check from President Arntsen. Below right are lupus advocates proudly holding our donation check at the LFA Summit.