

*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 16, Annual Edition October 2020--March 2022

## LADA SUPPORTS LOCAL LUPUS RESEARCH AGAIN

On September 22, 2021 the Masonic Medical Research Institute (MMRI) invited the Lupus and Allied Diseases Association Board and supporters for a personalized tour and preview of ongoing research efforts. The group was welcomed by Dr. Maria Kontaridis; Scientific Operations Manager, Jason McCarthy, PhD; Post-doctoral Fellow, Samantha Le Sommer, PhD; and the entire MMRI Team with open arms and of course, facemasks. The three researchers then shared presentation slides with the group on the MMRI's current research programs and answered questions.

because we were proud supporters of lupus research from 1990-1999 at the MMRI providing \$40,000 in funding. We are thrilled that lupus research has returned to Utica, NY and hope that MMRI's dedication and expertise will benefit people with lupus and allied diseases and look forward to the promising research results generated from our continued collaboration.

Research in autoimmunity specifically focusing on Systemic Lupus Erythematosus became a priority in 2018 at the MMRI with the recruitment of Dr. Maria Kontaridis, Executive Director and Gordon K. Moe Professor and Chair of the Biomedical Research and Translational Medicine. They were unaware that only 23 miles away from the MMRI in Verona, Lupus and Allied Diseases Association was busy working to raise funds to support lupus research. Thanks to news of Dr. Kontaridis' receipt of the Lupus Impact Award from the Department of Defense, the MMRI and LADA connected.

LADA President and CEO, Kathleen Arntsen, and Dr. Kontaridis had met years prior to this, at a lupus research conference in New York City. "It is amazing to see that after all these years, and coming to work for the MMRI here in Central New York, that Kathleen and I reconnected. This is a wonderful opportunity for all of us, working together in our shared goal to improve the lives of those living with lupus," said Dr. Kontaridis. All of us at LADA love the fact that lupus research is taking place once again in the Mohawk Valley. Not only do we advocate for the DOD Lupus Research Program each year along with the LFA, LRA and advocates from across the nation, but LADA was founded in 1978 in East Utica not far from the Institute by the Curri Family.



The event was set up by the MMRI after receiving a \$25,000 check for the continuation of their DOD-funded lupus research at LADA's Annual Lupus Charity Golf Classic in August. We were excited to learn about the innovative research that Dr. Kontaridis and the MMRI team are doing regarding lupus, especially since we have been part of the DOD Lupus Research Program since its inception, but even more importantly

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 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*

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- 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](mailto:Info@LADAInc.org) if you have questions regarding our privacy policy.

# ***The Lupus Communiqué***

*Is published once a year by  
Lupus and Allied Diseases Association, Inc.*

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## **DISCLAIMER**

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## **President's Message—**

Tomorrow is April Fool's Day which seems quite appropriate given that we are entering our 25th month of dealing with the pandemic. When COVID-19 began in 2020, none of us would have predicted that we would still be battling the virus two years later. To say that the past twenty-four months have been difficult is an understatement, and yet, despite the challenges we have endured, we remain cautiously optimistic about the future and encouraged 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. We are continually amazed and inspired by the resilience and resourcefulness that people with lupus and allied diseases and their loved ones, healthcare providers, and other patient advocacy organizations have demonstrated during these challenging times.

Although the winter weather and COVID-19 have been mutually unpredictable, we have successfully tolerated both while achieving another remarkable year of growth for the Lupus and Allied Diseases Association, Inc. We were able to expand our advocacy, education, awareness and research program initiatives and substantially increase our income in 2021. These achievements would not be possible without our many volunteers and supporters whom we recognize and thank for their time, expertise and generosity. I am incredibly honored to lead an organization of truly dedicated and passionate individuals who exemplify the importance of the patient and care partner viewpoint daily.

It has been personally rewarding to watch our evolution from the small Utica, NY group founded in 1978 with the goal to bring people affected by lupus together for support in the local area, to the current national organization dedicated to enhancing quality of life for individuals impacted by lupus and allied diseases and other conditions of unmet need. As an all-volunteer, patient-led, and passion-driven charity we have worked tirelessly for decades to ensure that the patient participant is included as an equal stakeholder in the healthcare, regulatory and public policy arenas and across the research continuum. We are recognized for our abilities to foster collaboration among stakeholders, promote unity in the community, and wield the patient voice as a catalyst to advance innovative advocacy, education, awareness and biomedical research initiatives. We are extremely proud of all that we have accomplished so far and look forward to a stellar 2022.

We invite you to partner with us by participating in our ongoing education, awareness and advocacy programs and to become engaged by making your voice heard on important healthcare access issues that impact you and your loved ones to ensure access to medical care and treatments and advance research that improves lives. Please visit our website <https://www.ladainc.org> to learn more about our programs and follow us on Twitter at @LADAorg and on Facebook and LinkedIn at Lupus and Allied Diseases Association, Inc.

Please join us in promoting May as Lupus Awareness Month by sharing and liking our daily *Did You Know* Lupus Facts social media posts and celebrating May 10<sup>th</sup> as World Lupus Day by participating in our *Hats On 4 Lupus* Awareness Campaign. Check out last year's photos on page 16 and click on the following link to learn more. <https://www.ladainc.org/world-lupus-day-tea>

Consider supporting our 22<sup>nd</sup> Annual Lupus Charity Golf Classic taking place on Thursday, August 18, 2022 at Shenendoah Golf Course at Turning Stone in Verona, NY beginning with Registration and Luncheon at 11:30AM, Modified Shotgun Start at 1:00PM and ending with the Awards Dinner at 6:00PM. Check out last year's event on pages 6-7. Please reach out if you have any questions or would like a Sponsor or Golfer Packet sent to you or feel free to visit our Golf Classic page on our website to download forms. <https://www.ladainc.org/golf-classic>

We are here for you and your loved ones in your lupus journey and look forward to a time when people with lupus and allied diseases have a better quality of life and the opportunity to fully pursue their dreams. We are extremely thankful for your engagement and support; after all, Lupus ends with Us!

**Stay Safe and Be Well—Kathleen**



## ***Lupus Education Symposium Road Show***

We are excited to announce that Lupus and Allied Diseases Association is in the process of taking our ***Enhancing Lives by Empowering the Lupus Community Education Symposium and Luncheon*** on the road again. We are partnering with Lupus Foundation New England in Boston, Massachusetts on October 2, 2022; the Michigan Lupus Foundation in Detroit, Michigan on October 15, 2022; and the Lupus Society of Illinois in Chicago, Illinois on October 29, 2022.

The program includes: Clinical Research Trials and Participation, Patient Empowerment, Treatment Access Challenges. The program is open to people with lupus and other autoimmune conditions, their loved ones, care partners, medical students, patient advocacy leaders, sponsors, and others interested in the topics. The event and luncheon are FREE but all attendees must register to attend.

To register visit: <https://www.ladainc.org/education-symposium-roadshow>

We would like to recognize and thank our sponsors for their generous support.

### **Platinum Luncheon Sponsor**

**Aurinia Pharmaceuticals, Biogen and UCB, Inc., and GlaxoSmithKline**

### **Gold Program Sponsor**

**AbbVie, AstraZeneca, Bristol-Myers Squibb, Equillum, Inc., Horizon Therapeutics, Janssen, and Mallinckrodt Pharmaceuticals**

## ***Lupus Awareness NYS License Plates***

Lupus Awareness License Plates are available to order until September 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. We thank NY State Senator Kevin Parker and Assemblymember Crystal Peoples-Stokes for sponsoring this legislation that was passed by the state legislature and became law.

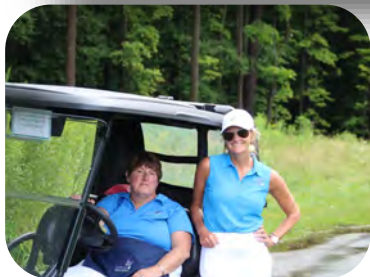
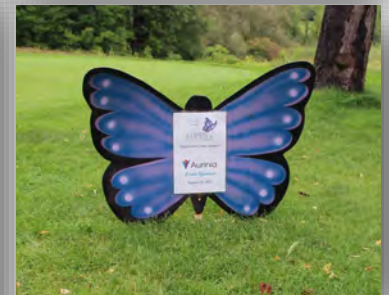
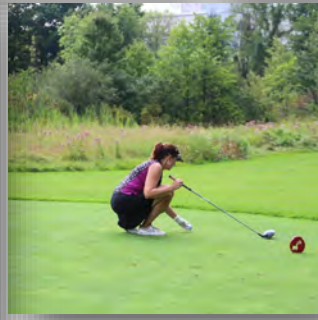
The goal of the awareness plates is to promote much-needed lupus awareness and education throughout the state, while monies received into the lupus research and education fund will be used to finance research to hopefully improve the quality of life for New York residents living with lupus. The awareness 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 plates can be ordered by telephone at (518) 402-4838 or online through the following link: <https://dmv.ny.gov/plates/lupus-awareness>





# 2021 GOLF CLASSIC





# 2021 GOLF CLASSIC WINNERS

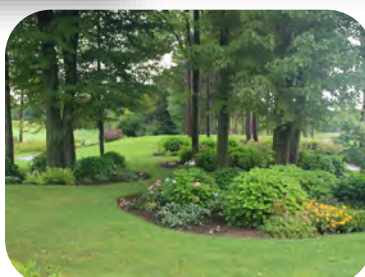


The 21st Annual Lupus Charity Golf Classic was held on August 19, 2021 at Shenendoah Golf Club at Turning Stone Resort in Verona, NY despite the rain and with safety precautions in place that included mandatory masks, social distancing, and no auction. More than \$119,000 gross and \$94,000 net was raised. Thank you to all of the golfers, sponsors, volunteers, and supporters who made the event a success.

## Closest to the Pin



## Longest Drive



## **ICER Lupus Nephritis Drug Review**

LADA has been actively engaged with the Institute for Clinical and Economic Review (ICER) from August 2020 to ensure that our unique viewpoint regarding the lupus patient journey was both included and recognized during their review of belimumab (Benlysta®, GlaxoSmithKline) and voclosporin (Lupkynis™, Aurinia Pharmaceuticals), two recently FDA-approved drugs in assessing their clinical effectiveness and value for the treatment of lupus nephritis.

The overall review is very positive for the lupus community as it shows value in both lupus nephritis treatments. This is a significant victory for us given that there are many lupus and lupus nephritis drugs in the pipeline right now that may be reviewed by ICER in the future and will need to be covered by payers.

As a patient-led organization, we fought very hard to ensure that the ICER Team listened to us regarding lifetime impacts to patient and caregiver lives on the topics of education, career and motherhood, as well as steroid sparing and health inequities.

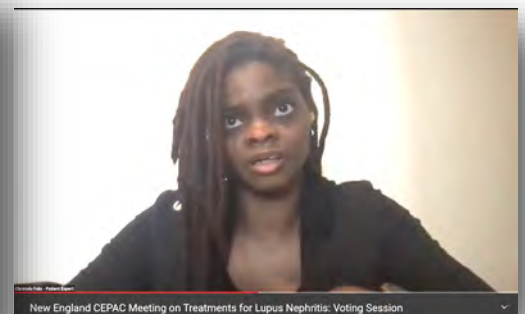
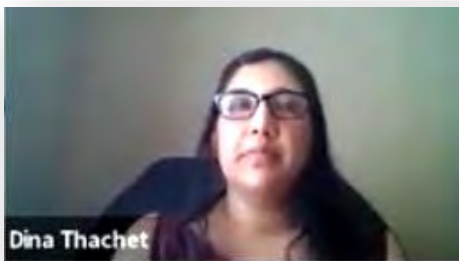
We provided written comments during each stage of the process to highlight the daily challenges and burden of disease over a person's lifetime, emphasizing what matters most to us as people living with the disease.

LADA President & CEO, Kathleen Arntsen had the privilege of serving as the Patient Expert Reviewer for the Draft Evidence Report and Draft Policy Recommendations Report. She also participated in the March CEPAC Meeting as a Patient Expert Panelist providing the patient and community perspective during the Meeting and Policy Roundtable along with LupusChat Chief Operating Officer Christele Felix.

LADA Patient Advocate Dina Thachet also participated in the Meeting by sharing her very compelling journey with lupus and struggles to be a Mother during the Public Comments portion.

LADA would also like to recognize and thank the Black Women's Health Imperative (BWHI), Aurinia and GSK Teams as well as Dr. Brad Rovin; Dr. Meggan Mackay; Linda Goler Blount, BWHI President & CEO; and Toni Grimes, LFA Advocate for their public comments and participation during the meeting and the ACR, LFA, and LRA and others who also provided input during the process.

We are happy to share the link below with you to learn more about the Lupus Nephritis Review, download materials or view the meeting and policy roundtable videos. <https://icer.org/assessment/lupus-nephritis-2021/#overview>



**Pictured above left: LADA Patient Advocate Dina Thachet sharing her personal journey with lupus and to be a Mother during the New England CEPAC Meeting Public Comments Session. Above Center: LADA President & CEO Kathleen Arntsen sharing patient and caregiver input as a Patient Expert Panelist during the New England CEPAC Meeting Voting Session. Above right: LupusChat Chief Operating Officer Christele Felix sharing her personal lupus and caregiver journeys as a Patient Expert Panelist during the New England CEPAC Meeting Voting Session.**



## ***Make Your Voices Heard Initiative***

LADA launched a novel patient advocacy program in late 2019, *Make Your Voices Heard*, an education and advocacy initiative designed to enlighten 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 and their community. This program focuses on the importance of people directly impacted by lupus and allied diseases becoming actively engaged in the advocacy process by turning their emotion into motion and outrage into action and using their voices as a catalyst to influence positive change.

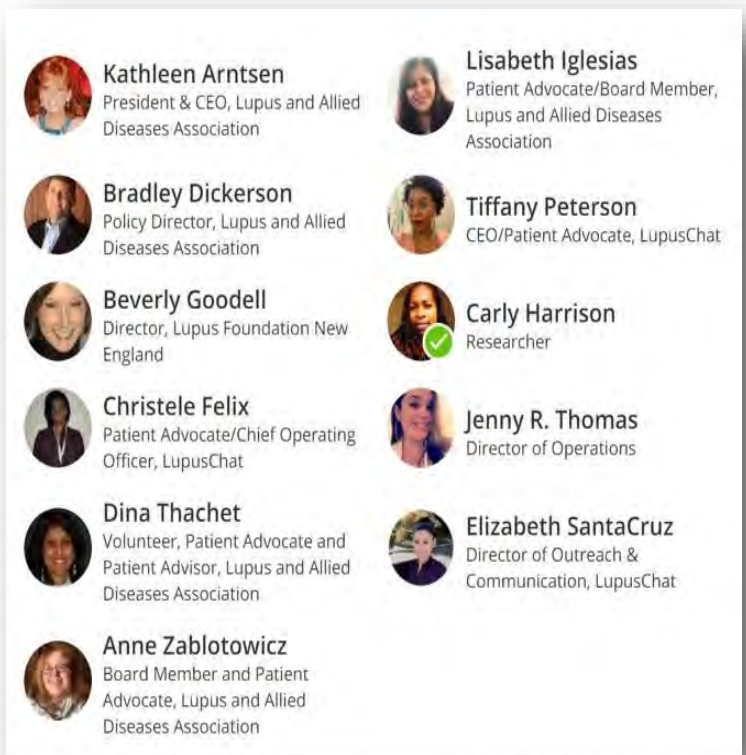
The *Make Your Voices Heard Initiative* also provides both virtual and in person opportunities for people with lupus and loved ones to attend important advocacy and scientific meetings in order to learn, network, and share their unique patient viewpoints while informing other attendees and then disseminating 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.

The ICER Meeting on the previous page is example of ways that LADA works with patient advocates to insert the patient voice into research as well as in the regulatory process and during the stages of the U.S. drug and device research and development process.

In addition, LADA sponsored the Lupus Exhibit at the American College of Rheumatology (ACR) Annual Scientific Meeting in November 2020 and 2021 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 is 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 our organizations. We appreciate the participation of the various groups: Lupus and Allied Diseases Association, LupusChat, and Lupus Foundation New England and the efforts of our invaluable volunteers.

We were thrilled that past two meetings had more patient representation than in previous years and were honored to sponsor LupusChat Executive Team Members Christele Felix, Tiffany Peterson and Carlene Harrison to participate in the Patient Perspectives Poster session in 2020. We will continue to provide opportunities for people with lupus to be present and at the table in these arenas by supporting their participation in key advocacy and scientific meetings.



**LADA gratefully acknowledges our sponsors for their generosity and support.**

### **Platinum Sponsors**

**AbbVie, Amgen, Aurinia Pharmaceuticals, and Mallinckrodt Pharmaceuticals**

### **Gold Sponsors**

**AstraZeneca, Horizon Therapeutics, and Janssen**

# Memorials, Tributes, and Donations

## Memorials

*In Loving Memory of...*

*James Edward and Patricia Ann Mitchell-  
David & Kathleen Arntsen*

*Marc R. Chevrier-  
LADA Board of Directors  
David & Kathleen Arntsen*

*Anne Stevens  
Carrie Wagner  
Pearl Pugh*

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*Chad Daly*

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*Michael Januszkeski*

*Medical Staff of Mercy Medical Center*

*Cynthia Arnold*

*Aubrey Sprabery*

*Allison Pirone*

*Bill & Sandi Frear*

*The Lupus Research Alliance*

*Looms for Lupus*

## Memorials

*In Loving Memory of...*

*Kenneth & Marian Arntsen-  
David & Kathleen Arntsen, Dan & Lois Rumpfelt*

*Isabel C. Woolshlager-  
David & Kathleen Arntsen*

*Judy Waligory, Susan Lex  
Peter & Mary Jane O'Connor  
Carol Virkler, Marietta Virkler*

*Peter & Nancy Marshall*

*Brian & Bonnie Oals*

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*Brian & Luann McAuliffe*

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*Larry & Kathy Scharf*

*Bill & Sandi Frear*

*Lisabeth Iglesias*



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## *Tributes*

*In Loving Honor of...*

*Cathy Walseman-  
Bob Walseman  
Jeffrey & Susan Virkler & Family  
Larry & Karen Woolshlager & Family*

*Jackie Taylor-  
UFCW District Union Local ONE*

*Sandi Frear-  
Friends & Family*

*Brian Vogel-  
Joseph & Lori Vogel, Ron & Sue Durgan*

*Maryrose Bullock-  
Friends & Neighbors*

*Francesca Rose-  
Family and Friends*

*Dina Thachet-  
Family & Friends*

## *World Lupus Day Tea*

*David & Kathleen Arntsen  
AstraZeneca Employees  
Tom & Jackie Taylor  
Bill & Sandi Frear  
Phil & Kathy Teague  
Lisabeth Iglesias  
Victoria Jupin in loving memory of Frank Jupin  
Jane Porter  
Helen Cassin  
Joseph & Lori Vogel  
Brian Vogel  
Ron & Sue Durgan  
Anne Zablotowicz in memory of Marc Chevrier  
Anne Zablotowicz in memory of Rebecca Scott  
Anne Zablotowicz in honor of NY Lupus Warriors  
Anne Zablotowicz in memory of Warrior Moms  
Dina Thachet  
Jeffrey Dobrinsky  
Karl, Saira & Amalia Lobo  
Amanda Greene  
Our many supporters who participated in Hats On 4 Lupus*

# *Memorials, Tributes, and Donations*

## Memorials

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*“Jimmy” James E. Mitchell Jr.,  
Timothy S. Mitchell-  
Jill Anne Smith*

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

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Linda Arntsen & Donald Arntsen-  
David & Kathleen Arntsen*

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Bill & Sandi Frear & Helen Cassin*

*Anita Curtiss-  
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*Elwood Virkler-  
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Larry & Karen Woolshlager & Family*

*Carol Honors-  
Larry & Karen Woolshlager & Family*

*Richie Hanlon-  
Larry & Karen Woolshlager & Family*

*Tom McCabe, Sr.-  
Larry & Karen Woolshlager & Family*

*Caroline Olsen-  
Paul Olsen, Karl Gaston*

## 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  
Amanda Marie Nemcek  
James E. & Mary Alice Mitchell  
Harold & Pat Leach  
William & Catherine Leach  
James E. & Elizabeth Mitchell  
Thomas P. Mitchell  
George Williams-  
David & Kathleen Arntsen*

*Brooke N. Walseman-  
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Jeffrey & Susan Virkler & Family  
Larry & Karen Woolshlager & Family*

*Marie Eignor-  
Bob & Cathy Walseman*

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

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Monica Falitico*

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

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

*Douglas Kerr-  
Bob & Cathy Walseman*

*Joseph Jupin-  
Victoria Jupin*

*Wellington & Doris Walseman-  
Bob & Cathy Walseman*



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National Infusion Center Association  
Donald Raddatz, MD  
Kristi Lengyel  
Takeda  
Beta Sigma Phi  
Scott Brewster  
Jane Porter  
Bill and Sandi Frear  
Helen Cassin  
Alliance for Patient Access  
Coalition of State Rheumatology Organizations  
Karl, Saira & Amalia Lobo  
Eli Lilly and Company  
Horizon Therapeutics, USA, Inc.  
Rheumatology Nurses Society  
Amanda Greene  
Patricia Sanicola  
ACR Lupus Initiative  
EMD Serono  
DxTerity  
UFCW District Union Local ONE  
Biogen  
Marwan Al-Haddad, MD  
Anne Zablotowicz  
Matt Harutunian  
Robert J. Ravitz  
Kevin Daley  
Idorsia  
Kezar Life Sciences  
Paul Olsen  
Jeffrey Dobrinsky  
New York Central Mutual  
Oneida Indian Nation  
CMI Audio Visual  
Color of Crohns & Chronic Illness  
International Foundation for Autoimmune &  
Autoinflammatory Arthritis  
Jeff Wait  
Equillum, Inc.*

## 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 our hope that research advancements lie ahead that will improve our lives. Therefore, we believe wholeheartedly in investing in quality research here at Lupus and Allied Diseases Association.

In 2021, LADA expanded our lupus research program investments by announcing our record year of giving to research at our 21st Annual Lupus Charity Golf Classic Awards Dinner held on August 19th at the Shenendoah Golf Course at Turning Stone Resort. LADA donated a record breaking \$289,705.00 to lupus research this year, bringing our overall total to \$1,373,705.00 since 1990.

During the Awards Dinner, we were thrilled to present Lupus Research Alliance (LRA) Representatives and Golfers Albert Roy, Dorey Neilinger, and Jonathan Marks with our 2021 annual research donation for \$120,000.00 to support Dr. Zahi Touma at University of Toronto for his Modeling Cognitive Impairment project and Dr. Joyce Chang at Boston Children's Hospital for her Pediatric Vascular Injury project. We are honored to say that we have now given \$831,050.00 in 20 years to support lupus research at the LRA.

We also presented Dr. Maria Kontarides and the Masonic Medical Research Institute (MMRI) Team with a check in the amount of \$25,000.00 to provide additional support for their DOD Lupus Impact Award Research Project on the Pathogenesis of Lupus. Since we had previously supported lupus research at the Institute from 1990 to 1999, this brings our total research support amount to MMRI up to \$65,000.00.

In addition, we had donated \$100,000.00 to the Lupus Foundation of America earlier in the year, designating \$50,000.00 to their promising Pediatric Research Program in partnership with the Childhood Arthritis and Rheumatology Research Alliance (CARRA) and \$50,000.00 to Dr. Gary Gilkeson for his Mesenchymal Stromal Stem Cell Research Program.

We also established the Marc R. Chevrier, MD, PhD, FACR, Lupus Research Memorial Fund at The Rheumatology Research Foundation (RRF) earlier this year. The fund will support lupus research funded within the Foundation's preceptorships program. (See article on page 15.)

We are poised to provide even more research funding in 2022 and thank all of our donors whose support makes our funding possible and thank and recognize the tireless scientists and their staff who are advancing lupus and autoimmune research with their amazing expertise and vision.



**Pictured above left are LADA Secretary David Arntsen (left) and President Kathleen Arntsen (right) presenting a \$120,000 lupus research donation to Lupus Research Alliance (LRA) Representatives Jonathan Marks, Dorey Neilinger, and Al Roy at the Golf Classic Dinner. Above right are LADA President & CEO Kathleen Arntsen (right) presenting a \$25,000 lupus research donation to Masonic Medical Research Institute (MMRI) Executive Director Dr. Maria Kontaridis and the MMRI Team at the Golf Classic Dinner.**



## LADA Establishes Lupus Research Fund to Honor Dr. Marc Chevrier

The Lupus and Allied Diseases Association, Inc. established the Marc R. Chevrier, MD, PhD, FACR, Lupus Research Memorial Fund at the Rheumatology Research Foundation (RRF) in March 2021 and just donated an additional \$30,000 to support this initiative in 2022. The fund was established to honor the life and legacy of Marc Chevrier, MD, PhD, FACR, a pioneer and patient advocate in the field of lupus and dear friend to all of us at LADA with the blessing of his wife Diane and family.

Marc's unexpected passing was a tremendous loss to the lupus and immunology communities, especially to the researcher and patient communities. He was incredibly passionate about improving the care of people with lupus and other autoimmune and rheumatologic diseases and dedicated his career to these pursuits. Marc was incredibly kind and generous, and was devoted to his loving family and many lifelong friends.

Marc was a speaker at several of our education events over the years, and enjoyed interacting with the patient community at education and scientific meetings. Known for his jovial personality and long beard, he was fondly nicknamed *Papa Lupus* during the 2019 Lupus International Meeting.

"The worldwide lupus and rheumatology communities lost a brilliant scientist, caring clinician, innovative educator, and passionate advocate with the recent passing of our dear friend Dr. Marc Chevrier. We are honored to partner with the Foundation to establish this fund in Marc's name to support novel lupus research," said Kathleen A. Arntsen, President & CEO of Lupus and Allied Diseases Association, Inc., "Marc was respected by all who knew him, but to those of us living with lupus, *Papa Lupus* was our hero; giving us strength and hope that better treatments were just around the corner."

We are humbled by the generosity and benevolence of the Chevrier Family during an incredibly difficult time in their lives by selecting LADA to receive donations in Marc's memory. This led us to establish the Marc R. Chevrier, MD, PhD, FACR, Lupus Research Memorial Fund at the RRF. All memorial funds received by LADA in Dr. Chevrier's name will support lupus research funded within the Foundation's preceptorships program and we are thrilled that it has grown to \$74,805 since its inception.

The inaugural award project explores interventions to reduce fatigue in systemic lupus erythematosus (SLE). Award recipients, Thomas Farrar, BS and Shanthini Kasturi, MD from Tufts University, hypothesize that educational modules specifically developed to address patient-derived barriers to combating fatigue in SLE will be effective in reducing lupus-related fatigue.

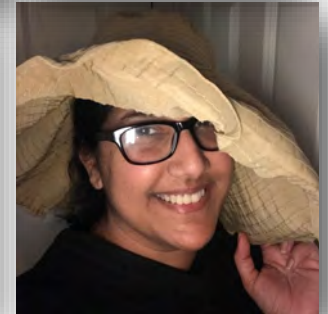
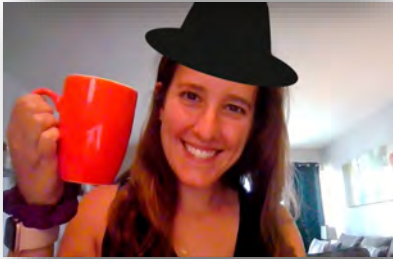
"Exposing physicians to lupus early in their careers is so important for general awareness of the disease and for maintaining the pipeline in rheumatology," said Shanthini. "I am thrilled this preceptorship makes it possible for motivated medical students to learn about SLE through meaningful clinical and research experiences."

"It is truly an honor to have received the first ever Marc R. Chevrier, MD, PhD, FACR, Lupus Research Memorial Fund award," said Farrar. "I am so grateful for this funding that has allowed me to both pursue a passion of mine and work towards a promising program to reduce fatigue in individuals with lupus."

We are thankful to everyone who has supported the fund so far and hope that others will continue to do so in honor of Dr. Chevrier. To support or learn more about the Marc R. Chevrier, MD, PhD, FACR, Lupus Research Memorial Fund visit the Donations page on our website and make a donation through Network for Good at <https://www.ladainc.org/donate>







# HATS ON 4 LUPUS ON MAY 10TH WORLD LUPUS DAY

