RECORD BREAKING YEAR OF RESEARCH SUPPORT

The Lupus and Allied Diseases Association supported two research grants totaling $200,000 in 2018 which makes it a record breaking year for us in research support. We are very proud to have now supported $764,000 in research funding overall to date. We donated $100,000 to the Lupus Foundation of America in March for their promising pediatric research program and mesenchymal stem cell research program and $100,000 to the Lupus Research Alliance in August for their innovative lupus and autoimmune research program. Pictured above left is LADA’s President & CEO Kathleen Arntsen presenting our large check for $100,000 to Dr. Gary Gilkeson, from the Medical University of South Carolina (center) and LFA President & CEO Steve Gibson (right) at the LFA Advocacy Summit in Washington, DC. In the photo above right are Lupus Research Alliance President & CEO Ken Farber (far left) and Board Secretary Robert Ravitz (middle left) and LADA’s President & CEO Kathleen Arntsen (middle right) and Board Secretary David Arntsen (far right) presenting the $100,000 donation at the Lupus Research Alliance Annual Scientific Meeting in New York City.
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 David at 315-829-4272 or by e-mail at Info@LADAinc.org if you have questions regarding our privacy policy.
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www.LADAinc.org

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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 President & CEO of this organization, I am filled with extreme pride while sitting here reflecting on our accomplishments over the past 12 months and waiting for the clock to strike midnight to officially launch Lupus Awareness Month. We achieved another outstanding year of growth in income for the Lupus and Allied Diseases Association, allowing us to expand our existing programs and launch new ones. Once again, our many volunteers and supporters stepped up, continuing to amaze us with their generosity and kindness, and far exceeding our expectations.

In the past year we continued to promote patient-centered care, 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 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 supported lupus and autoimmune research programs that will hopefully identify causes, advance better diagnostics, and lead to the discovery of superior treatments, and cures. You can read about our various programs throughout the newsletter.

As we enter our 41\textsuperscript{st} year of existence as an all-volunteer, passion-driven charity led by individuals with lupus and their loved ones, we look forward to continuing to enhance quality of life by engaging, enlightening, empowering and elevating the lupus and allied diseases community. We invite you to partner with us by participating in our innovative empowerment programs and advocacy initiatives to establish strong patient safeguards and improve access to health care. Please help us to drive biomedical research and development forward with the patient viewpoint at the table as an equal stakeholder.

We encourage you to join us at one of our upcoming events listed in the newsletter such as our 11\textsuperscript{th} Annual Lupus Awareness Day in the NYS Capitol on May 8\textsuperscript{th}, World Lupus Day on May 10\textsuperscript{th}, Clinical Trials Awareness Day on May 20\textsuperscript{th}, the August 22\textsuperscript{nd} Lupus Charity Golf Classic, or the October 5\textsuperscript{th} Education Symposium. Most importantly, we invite you to become engaged in our ongoing awareness and advocacy programs to make your voice heard on important research and health care access issues that impact you and your family.

Please visit our new website \url{www.LADAinc.org} and follow us on Twitter or Facebook @LADAorg. We are here for you and your loved ones as you continue on your lupus and allied diseases journey and look forward to a time when people with lupus and autoimmune conditions have a better quality of life and the opportunity to pursue their dreams. We are grateful for your involvement and support; after all, Lupus ends with Us!

We are small but mighty and march among giants!

\textit{Here’s to a Glorious Spring and Summer—Kathleen}
May is Lupus Awareness Month

Lupus and Allied Diseases Association will be joining with the other members of the Lupus Agencies of New York State for the 11th Annual Lupus Awareness Month Recognition in Albany, NY in the State Capitol in both the Senate and Assembly Chambers on Wednesday, May 8, 2019. Senator Joseph Griffo and Assemblymember Fred Thiele will continue to sponsor the joint legislative resolutions.

The groups have been coming to Albany each May for the past eleven years to increase public education and awareness of Lupus and its impact and to garner support for lupus education and research programs and access to health care and treatment issues.

The Lupus Agencies of New York State extend our sincere appreciation to our Legislative Resolution Sponsors, our Senate and Assembly hosts and their staff for making the annual event possible.

We also acknowledge the following sponsors—**AbbVie, AdvaMed, Genentech, and Mallinckrodt** for their generosity in supporting our advocacy program and thank our dedicated lupus advocates for attending.

The Lupus and Allied Diseases Association is honored to be a member of the World Lupus Federation and participating in the 15th annual observance of World Lupus Day on May 10, 2019 along with 200 lupus groups from around the world.

A global health problem, lupus affects people of all nationalities, races, ethnicities, genders, and ages. While lupus knows no boundaries, knowing all you can about lupus can help control its impact.

To learn more about the effort visit worldlupusday.org and make sure you sign the petition to make lupus a priority to the WHO and read the global report.

For more information visit **WorldLupusDay.org**
LADA Launches 2 New Education Programs in 2019

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 on the road to Hawaii, California and Colorado this year. The purpose of this initiative is to provide an educational program on Clinical Research Trials and Participation, Patient Empowerment, an Overview of Biological Drugs, Infusions, Treatment Access Challenges, and Tools for Survival when Dealing with Chronic Disease. A list of regional lupus clinical trial opportunities, patient empowerment and advocacy resource materials and a list of current healthcare access efforts are available for distribution. We chose to hold our event in three areas in the United States where there is a need for greater knowledge of the topics being presented. The program is FREE but people must register to attend.

We have now held 2 of the 3 events and they were a tremendous success based on the input we received from attendee evaluations so far. The first program was held on Saturday, March 30, 2019 at the Ko’olau Ballrooms & Conference Center in Kaneohe, HI and was hosted by Sjögren's Lupus Foundation of Hawaii (SLFH), and Lupus and Allied Diseases Association (LADA). The second program was held on Wednesday, April 3, 2019 at the San Francisco Marriott Fisherman’s Wharf in San Francisco, CA and was hosted by Looms for Lupus, Lupus and Allied Diseases Association (LADA), and More Than Lupus.

Each symposium included an interactive word cloud representative of the attendees’ reactions to the education program.

The Colorado Symposium will be held on:
Saturday, October 5, 2019 from 10:00am to 2:30pm
Arapahoe Community College  Summit Room
5900 S. Santa Fe Drive  Littleton, CO  80120
Hosted by Lupus and Allied Diseases Association and Lupus Foundation of Colorado
To register for the Symposium and Luncheon visit
https://www.classy.org/event/enhancing-lives-by-empowering-the-lupus-community/e225679

We sincerely appreciate the generous support of our Education Symposium Sponsors

HOPE IS ON THE HORIZON PROJECT SPONSOR
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GOLD PROGRAM SPONSORS
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Eli Lilly
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Exagen Inc.
LADA launched *Enhancing Lives By Amplifying the Patient Voice*, a new patient-focused education initiative in January 2019. The objective of this program is to provide an opportunity for people with lupus 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 and rheumatology communities. The national meetings include: The Lupus Foundation of America (LFA) Annual Advocacy Summit in Washington, DC; the Lupus 2019 International Meeting in San Francisco, CA; and the American College of Rheumatology (ACR) Annual Scientific Meeting in Atlanta, GA.

We gratefully acknowledge the generous support of our Patient Voice Program Sponsors

**GOLD LEVEL SPONSORS**
- Celgene
- Mallinckrodt Pharmaceuticals

**BRONZE LEVEL SPONSORS**
- Biotech Innovation Organization (BIO)

Pictured below going clockwise: Hawaii Symposium attendees and speakers, Lupus 2019 word cloud, lupus warriors from around the world at the International Lupus Meeting, Hong Kong Lupus Warrior Sapphire Shen sharing her advocacy efforts during the Patient Voice session at Lupus 2019, and San Francisco Symposium hosts Kelli Roseta & Christine Von Raesfeld from More than Lupus, Kathleen Arntsen from LADA, Estela & Juana Mata from Looms for Lupus and David Arntsen from LADA with their word cloud.
The 18th Annual Lupus Charity Golf Classic was held on August 23rd, 2018 at Shenendoah Golf Club at Turning Stone Resort in Verona, NY. More than $103,000 gross and $83,000 net was raised to support our awareness, education, advocacy, and research program services. Thank you to all of the golfers, sponsors, prize donors, volunteers, and supporters who made the event possible.
19th Annual

Shenendoah Golf Course
at
Turning Stone Resort

Thursday, August 22, 2019

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, Ladies, Senior and Co-Ed Categories

Early Registration by July 22nd $175 per golfer
Registration after July 22nd $200 per golfer

Sponsorship Opportunities Available

Help to Make a Difference for those Affected by Lupus
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 Kathleen@LADAinc.org
or visit our website www.LADAinc.org
NINETEENTH ANNUAL
LUPUS CHARITY GOLF CLASSIC
AUGUST 22, 2019
Shenendoah Golf Course
Turning Stone Resort

SPONSORSHIP FORM

Corp. Name: ____________________________________________
Contact: _______________________________________________
Address: _______________________________________________
City/ State/ Zip: __________________________________________
Phone: ___________________________ E-mail: _______________________

☐ $15,000 EVENT Sponsor — Complimentary Foursome, logo display on event &
promotional materials, dinner tables, carts, banner display, tee sign, program listing,
dinner recognition

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Tee sign, program listing ☐ Other Donation __________________________

*All complimentary foursomes include 18 holes of golf w/cart, lunch, and dinner for four. For more
information call: 315-829-4272 or 1-866-2-LUPUS-4 or E-mail Info@LADAinc.org

Please make checks payable to: Lupus Association
PO Box 170 Verona, NY 13478
An Invitation to Celebrate World Lupus Day

WHAT: Victorian Tea
WHERE: Your Home
WHEN: May 10, 2019

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 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 Info@LADAinc.org.
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

Eleanore Iglesias, Daniel Iglesias,
Frank Iglesias, Jr., David Iglesias, Jr.
& Eunice Mari Buck-
Lisabeth Iglesias & Francine Iglesias-Tosti

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

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-
James & Patricia Mitchell
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-
James & Patricia Mitchell
David & Kathleen Arntsen

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

Franklin Morrissey
Frederick Morrissey

Ethel Clark, Leona Sargent-
Isabel Woolshlager

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
Memorials, Tributes, and Donations

Memorials
In Loving Memory of…

Mary Margaret Della Posta-
David & Kathleen Arntsen

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

Frances Eck-
David & Kathleen Arntsen

Catherine Joan Gloo-
David & Kathleen Arntsen

Caroline Olsen-
Paul Olsen

Joseph Jupin-
Victoria Jupin

Bill Brooks-
Marion Brooks, Pat & Don Lane
STV Philadelphia Office
STV New Jersey Office

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Rocco & Monica Falitico
Janice Kullman

Harry & Angela Agens
Agnes St. Thomas & Family
Jim & Tina Gaffney
Bill, Joan & Debbie Penti
Geri Lemke, Patricia Currier
Class of 61 Lunch Bunch
Sheila B. Wilson
Aurora & Lorraine Wilson
Charles & Jean Canada

Coramae Mikitin-
Skenandoah Chapter, NSDAR
International Wire Group, Inc.
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Brian & Donalyn Dixon
Patricia Davis, Wendy Davis
Mystic Stamp Company

Jamie Shaffer-
Suzanne Carvell
Ann Falvey
The Utica Curling Club

Tributes
In Loving Honor of…

Monica & Rocco Falitico,
Geri Lemke, Roxanne Falitico-
Virginia Merola

Cathy Walseman-
Bob Walseman & Isabel Woolshlager

Monica Falitico-
Virginia Merola

Jackie Taylor-
UFCW District Union Local ONE

Sandi Frear’s Birthday-
Friends & Family

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Joseph & Lori Vogel, Ron & Sue Durgan
Wayne Towne, Mike Phillips, Steve Mack

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

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

World Lupus Day Tea

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

Marion Brooks in honor of Shane Perry
Cynthia Donaldson
Jane Williams

Victoria Jupin in loving memory of Frank Jupin
Helen Cassin
Jane Porter
Rick Deyulio
Samantha Darwak
Laurie Domanico
Memorials, Tributes, and Donations

Donations


Donations
