RECORDBREAKING RESEARCH SUPPORT

The Lupus and Allied Diseases Association supported two research grants in 2017 totaling $100,000 which makes it a recordbreaking year in research support. We are very proud to have now supported $464,000 in research grants overall. We donated $25,000 to the Lupus Foundation of America in July for their promising pediatric research program and $75,000 to the Lupus Research Alliance in October for their innovative lupus and autoimmune research program. Pictured above are LADA’s Secretary David Arntsen (far left) and President & CEO Kathleen Arntsen (middle left) presenting the $75,000 donation to Lupus Research Alliance Board Secretary Robert Ravitz (middle right) and President & CEO Ken Farber (far right) at the Lupus Research Alliance Annual Scientific Meeting in New York.
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.
TABLE OF CONTENTS

Research Donation 1
Newsletter Information 2
Organization Information 3
President’s Message 4
Lupus PFDD Article 5
Education Symposium 6
Research and Events 7
Golf Classic Photos 8-9
Golf Classic Poster 10
Golf Classic Form 11
May WLD Victorian Tea 12
Memorials, Tributes & Donations 13-15
Awareness & Advocacy Photos 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 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.
We are thrilled that today marks the beginning of a very promising Lupus Awareness Month throughout the country. It’s hard to believe that it’s May since it was still snowing here yesterday in Central New York State. Although the winter weather was unforeseen and brutal, we survived while achieving another tremendous year of growth for the Lupus and Allied Diseases Association. We were able to expand our advocacy, awareness and research program initiatives and substantially increase our income in 2017. We thank our many volunteers and supporters for their time, expertise and generosity, which continue to exceed our expectations. It has been personally rewarding to watch our evolution from the small Utica, NY group founded in 1978 to bring people affected by lupus together 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, passion-driven and patient-focused charity led by individuals with lupus and their loved ones, we promote patient-centered healthcare, patient-engaged research and awareness programs in order to ensure that the patient perspective is included and recognized as an equal voice in healthcare and across the research continuum. It is our goal to improve access to healthcare and quality of life by fostering collaboration among stakeholders and supporting innovative advocacy, education, awareness and biomedical research initiatives that will identify causes, and discover better diagnostics, superior treatments, and cures. We are extremely proud of all that we have done and look forward to a stellar 2018.

Our recent activities include:

- Co-leading the effort for the lupus community collaboration on the FDA Patient-Focused Drug Development (PFDD) Initiative with the Lupus Foundation of America and the Lupus Research Alliance
- Providing 51 support letters, op-eds, media interviews, and testimony in 34 states to date on biologic medications, step therapy, non-medical switching, prescriber prevails, tier pricing, high co-pays, formulary changes, pbm transparency and other important access issues
- Providing public comments to CMS regarding Medicare Parts B and D and Medicaid issues
- Participating as a Member of 22 National and 17 State Coalitions
- Supporting advocacy efforts for FDARA Reauthorization, ACA Support, NIH & DOD Funding, Raise the Sequestration CAPS, ARHQ & CHIP Programs and other national issues
- Participating as a Steering Committee Member for the Biosimilars Stakeholder Workshop
- Leading Lupus Awareness Days in the NYS Capitol Complex Annually
- Participating as a Global Advisory Committee Member of the Addressing Lupus Pillars for Health Advancement (ALPHA) Project
- Providing public comments to the FDA, WHO and FTC regarding biologic medications
- Co-leading advocacy efforts in New York state resulting in legislation for Lupus Education & Outreach, Lupus Awareness, Step Therapy Reform and Biologic Substitution becoming law

We invite you to partner with us by participating in our research, education, awareness, and empowerment programs and advocacy initiatives to establish strong patient safeguards and access to medical care. Please help us to drive biomedical research and development forward with the patient perspective at the table as an equal stakeholder. We encourage you to join us at our current upcoming events listed in the newsletter: the May 12th Education Symposium, our 10th Annual Lupus Awareness Event in the NYS Capitol on May 23rd, or the August 23rd Lupus Charity Golf Classic, and we invite you to become engaged in our ongoing awareness and advocacy programs to make your voice heard on important research and healthcare access issues that impact you and are listed on our website www.Nolupus.org and on twitter@LADAOrg. Please stay tuned though because we are launching a new website this summer that better represents us—www.LADAinc.org

We are here for you in 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 fully pursue their dreams. We are extremely thankful for your involvement and support; afterall, Lupus ends with Us!

We are small but mighty and march among giants!

Hope for a Spectacular Spring and Be Well—Kathleen
We are pleased to announce the release of Lupus: Patient Voices, a comprehensive report based on input from the Externally-led Lupus Patient-Focused Drug Development (PFDD) Meeting and pre-meeting survey conducted last fall. This report includes data and personal accounts from people with lupus on symptoms, daily disease impacts, current treatments, and views on clinical trials. The report has been shared directly with the Food and Drug Administration (FDA) to help advance treatments for lupus.

The Lupus PFDD Initiative began over two years ago when the FDA responded favorably to a letter of intent to host an externally-led PFDD meeting submitted by the lupus community. Last summer, over 2,100 people completed a survey about their experiences with lupus, yielding important data about disease symptoms and treatments. On September 25, 2017, over 300 people with lupus and their representatives attended the Lupus PFDD Meeting in Hyattsville, MD and nearly 300 more participated via a live webcast. The meeting presentations, facilitated discussions, and post-meeting comments informed the content of the Lupus: Patient Voices Report.

This report is considered patient experience data, meaning that it can be used by the FDA during the review and approval process of new drugs for lupus. We hope that this report will help the FDA to better understand the perspectives and experiences of people with lupus and advance superior treatments for this devastating disease.

We are grateful to everyone who helped to make this report possible including the many lupus organizations across the country, researchers, clinicians, the FDA, our biopharmaceutical sponsors, and, most of all, people with lupus and their loved ones.

The Lupus: Patient Voices Report and the Lupus PFDD Meeting are the result of a collaboration between the Lupus and Allied Diseases Association, the Lupus Foundation of America, and the Lupus Research Alliance. To learn more about the Lupus PFDD Initiative, please visit lupuspfdd.org

An Amazing History-Making Event
Education Symposium & Luncheon

Enhancing Lives by Engaging, Empowering and Elevating the Lupus Community

Saturday, May 12, 2018
10:00am to 2:00pm
OCM BOCES Main Campus, Seneca Large Room
4500 Crown Road, Liverpool, NY 13090

Wellness Checks

Presenters include:

Andras Perl, MD, PhD
Rheumatologist & Clinical Researcher
An Overview of Clinical Research Trials

Kathleen A. Arntsen, National Patient Advocate
The Power of Advocacy: Promoting Participation to Improve Care and Advance Research

David Arntsen, Educator, Administrator and Advocate
“I Love Someone with Lupus, So…”

Massage Therapy

We extend sincere gratitude to our Event Sponsor:

Exhibit Booth Displays and Handouts

Aurinia Pharmaceuticals

Clinical Trial and Prescription Assistance Information

No cost. Registration is required.
Register at: www.LupusLearning.org

For information call (800) 300-4198, Ext. 1 or email info@lupusupstateny.org
Dr. Donald Raddatz, Division Chief of Rheumatology at Bassett Medical Center and Honorary Chairman of our Lupus Charity Golf Classic for the past 16 years, surprised us with a donation of $1,190.00 on August 5, 2017. The monies came from Bassett Healthcare Rheumatology Research Funds that had been established in the 1980’s for use in SLE and Rheumatologic Disease Research. Both Dr. Raddatz and Bassett Healthcare decided to close the account and donate the funds to LA-DA. Thank you to both Dr. Raddatz and Bill Stamp from Bassett Healthcare for their generosity in supporting our organization.

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, 2018 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.

**Do You Have Lupus Nephritis?**

The **Aurora Clinical Study** is now enrolling participants with active lupus nephritis.

For more information about this clinical trial, please email clinicaltrials@aurinapharma.com or visit [www.auroralnstudy.com](http://www.auroralnstudy.com).

**About Aurinia**

Aurinia is a clinical stage biopharmaceutical company focused on developing therapies for people that are suffering from serious diseases with a high unmet medical need. The company is currently developing an investigational drug for the treatment of lupus nephritis.

© 2018 Aurinia Pharmaceuticals Inc. All Rights Reserved.

**DO YOU OR SOMEONE YOU KNOW HAVE LUPUS?**

A STUDY EVALUATING THE EFFICACY AND SAFETY OF AN INVESTIGATIONAL DRUG IN SUBJECTS WITH ACTIVE SYSTEMIC LUPUS ERYTHEMATOSUS IS NOW ENROLLING.

**Qualified Subjects Must:**

- Be 18 years of age and older
- Have Lupus for at least 6 months
- Be able to attend clinic visits over a period of about 56 weeks
- Agree to use appropriate birth control measures during the study
- Be on a stable dose of lupus medications
- Have no other significant diseases or conditions

**SUNY Upstate Medical University**, 750 East Adams Street, Syracuse, NY 13210 – 315-464-4194
17th ANNUAL LUPUS CHARITY GOLF CLASSIC
The 17th Annual Lupus Charity Golf Classic was held on August 24th, 2017 at Shenendoah Golf Club at Turning Stone Resort in Verona, NY. More than $90,000 gross and $72,000 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.
18th Annual

LUPUS Charity Golf Classic

Shenendoah Golf Course at
Turning Stone Resort

Thursday, August 23, 2018

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 23rd $175 per golfer
Registration after July 23rd $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.nolupus.org
EIGHTEENTH ANNUAL
LUPUS CHARITY GOLF CLASSIC
AUGUST 23, 2018
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

☐ $10,000 DIAMOND Sponsor – Complimentary Foursome, logo display on
   event, dinner tables, carts, banner display, tee sign, program listing, dinner
   recognition

☐ $6,000 DINNER Sponsor – Complimentary Foursome, logo display on dinner
   tables, banner display, tee sign, program listing, dinner recognition

☐ $4,000 TOWEL Sponsor – Complimentary Foursome, logo display on towels,
   banner display, tee sign, program listing, dinner recognition

☐ $3,500 LUNCHEON Sponsor – Complimentary Foursome, logo display on
   luncheon counter, banner display, tee sign, program listing, dinner recognition

☐ $1,000 PLATINUM Sponsor – Complimentary Foursome, banner display, tee
   sign, program listing, dinner recognition

☐ $500 GOLD Sponsor ☐ $250 SILVER Sponsor ☐ $100 BRONZE Sponsor
   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, 2018

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 W. & Penny L. Cassin-
Helen E. Cassin

Barbara M. & Robert E. Porter-
Bill & Sandi Frear & Jane Porter

Barbara M. Porter-
Helen E. Cassin & John Zeock

Isabell Zeock-
John Zeock

Charles F. Carter
in honor of Cathy Walseman-
Jack & Marcia Flint

Eleanore Iglesias, Daniel Iglesias-
Lisabeth Iglesias & Francine Iglesias-Tosti

James & Rose McCarthy
Anita Curtiss, Carol Honors-
Larry & Karen Woolshlager & Family

Elwood Virkler-
Jeffrey & Susan Virkler & Family

Anita Russell-
Brigid Russell

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-
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

Anita Russell-
David & Kathleen Arntsen

Annie Ravitz-
David & Kathleen Arntsen

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

Mary Alice Mitchell, James E. Mitchell
Thomas P. Mitchell, George Williams-
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
- Marie Sanders Oriolo
  - Mr. & Mrs. Philip Cittadino
  - David & Kathleen Arntsen
- Louis Smith, Christine Marie Smith
  - David & Kathleen Arntsen
- Frances Eck
  - David & Kathleen Arntsen
- Catherine Joan Gloo
  - David & Kathleen Arntsen
- Geraldine Tocco
  - David & Kathleen Arntsen
  - Mary Ann Balaska
  - David & Josephine Hayes
  - Ann M. Tomarchio
  - Robert & Vicki Squire
  - Sandra Treen & John Synek
  - Samuel & Florence DiPrima
- Joanne Morse
- George & Ann Marie Treen
- Regina Wohan
- Salvatore & Rosalia Tocco
- Frank Soja
- Darryl & Jamie Ferguson
- Catherine Barretta
- Thomas & Kathleen Grates
- Joseph & Beatrice Tocco
- Steven & Carrie McMurray
- Patrick & Janet Doolen
- Gary & Cathy Loiacono
- Thomas & Lisa Della Posta
- Mario & Carla Pumilio
- David & Linda Tripoli
- Patsy & Joan Tomaino
- George & Rose Marie Surace
- Jerome & Dorothy LaMonica
- Vincent & Margaret Filingeri
- James & Phyllis Caruso
- Nina Rumrill, Doris Ludwig
- Frank & Debbie Roe & Family

## Tributes

*In Loving Honor of…*

- Geri Lemke, Roxanne Falitico
  - Virginia Merola
- Monica & Rocco Falitico
  - Virginia Merola
- Cathy Walseman
  - Bob Walseman, Isabel Woolshlager
  - Kim M. Gilbert, Kathleen Marshall
  - David & Kathleen Arntsen
  - Nick & Rae Ellen Castellone
  - Jeffrey & Susan Virkler & Family
  - Laury Kerr, Jack & Marcia Flint
- Kaamilah Gilyard’s Birthday
  - David & Kathleen Arntsen
- Brian Vogel
  - The Vogel Family
  - Ron & Sue Durgan
- Kathleen Arntsen
  - Jane Williams
- Jackie Taylor
  - UFCW District Union Local ONE

## 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
- Cynthia Donaldson
- Jane Williams
- Victoria Jupin in loving memory of Frank Jupin
  - Helen Cassin
  - Jane Porter
  - Rick Deyulio
- William & Julia Mitchell
- Laurie Famolaro
- Carol Walker
Memorials, Tributes, and Donations

Donations


Donations

Helen Sarandrea, Physical Therapy Sonbyrne Sales/Byrne Dairy Mark O’Rourke, Esq. Marc & Diane Chevrier Bob Walseman & Isabel Woolshlager Senator David Valesky Assemblyman Anthony Brindisi The Vandervort Group, LLC Aurinia Pharma UCB Lupus Research Alliance Rocco & Monica Falitico Bristol-Myers Squibb EMD Serono Mallinckrodt Pharmaceuticals U.S. Pain Foundation Pfizer Foundation Global Healthy Living Foundation National Infusion Center Association Donald Raddatz, MD Kristi Lengyel Rational PR, LLC Stanley & Peggy Ostergren Michael Donohoe Susan Fraser, MD Takeda Matt Badalucco Donald Raddatz, MD AdvaMed Beta Sigma Phi Steve & Amanda Greene Oneida Indian Nation/Turning Stone Resort High Peaks Resort Golden Arrow Lakeside Resort Celgene Brigid Russell Lake Placid Crowne Plaza Golf Club Vernon Downs Casino Holiday Inn-Utica Love’s of Rome Yahnundasis Golf Cub Colgate University Seven Oaks Golf Club Betty Servatius AARDA Scott Brewster Jane Porter Bill and Sandi Frear Helen Cassin