



*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 13, Annual Edition 2017

## 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.

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***

#### **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](mailto:Info@LADAinc.org) if you have questions regarding our privacy policy.**

# ***The Lupus Communiqué***

***Is published once a year by  
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***www.NoLupus.org***

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## **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.

## **BOARD OF DIRECTORS**

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*Rheumatologist*

## ***President's Message—***

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 one of our upcoming events listed in the newsletter: the May 12<sup>th</sup> Education Symposium, our 10<sup>th</sup> Annual Lupus Awareness Event in the NYS Capitol on May 23<sup>rd</sup>, or the August 23<sup>rd</sup> 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](http://www.NoLupus.org) and on [twitter@LADAorg](https://twitter.com/LADAorg). Please stay tuned though because we are launching a new website this summer that better represents us-- [www.LADAinc.org](http://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***



## Lupus: Patient Voices Report Released

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.

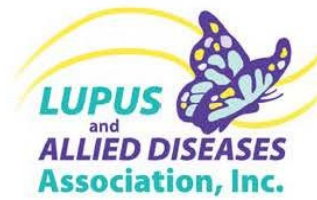
The *Lupus: Patient Voices* Report and the Lupus PFDD Meeting are the result of a collaboration between the Lupus and Allied Diseases Association, the Lupus Foundation of America, and the Lupus Research Alliance. To learn more about the Lupus PFDD Initiative, please visit [lupuspfdd.org](http://lupuspfdd.org)



**An Amazing History-Making Event**



Hosted By



Contributing Partner

## 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:**

**Massage  
Therapy**

**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..."***

*We extend sincere gratitude to our Event Sponsor:*

**Exhibit  
Booth  
Displays  
and  
Handouts**



**Clinical Trial  
and  
Prescription  
Assistance  
Information**

**No cost. Registration is required.**

**Register at: [www.LupusLearning.org](http://www.LupusLearning.org)**

For information call (800) 300-4198, Ext. 1 or email [info@lupusupstateny.org](mailto: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](http://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@auriniapharma.com](mailto:clinicaltrials@auriniapharma.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.





## 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





# 2017 GOLF CLASSIC WINNERS



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.

## Closest to the Pin



## Longest Drive





*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

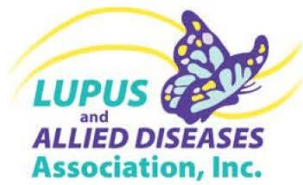


**Help to Make a Difference for those Affected by Lupus  
While enjoying a great round of golf**

**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](mailto:Kathleen@LADAinc.org)  
or visit our website [www.nolupus.org](http://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 the our cause this Spring by participating in our ***World Lupus Day Victorian Tea***. Proceeds from this non-event will be used to fund our Organization's Program Services:

Newsletter Printing & Postage

Lupus Awareness, Advocacy and Public Education Programs

Continued Training to update our leaders on current information

Distribution of lupus materials for awareness events

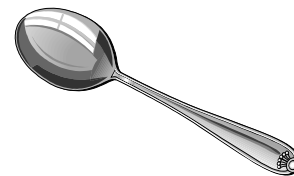
Telephone hotline and website

*Please make checks payable to:*

***Lupus and Allied Diseases Association***

***PO Box 170***

***Verona, New York 13478***



***Thank you for your Consideration and Support!!!***

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

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*The Reverend S. Kenneth Arntsen,*

*Linda Arntsen & Donald Arntsen-*

*David & Kathleen Arntsen*

*Marian J. Arntsen*

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*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*

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*Marie Eignor-*

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*Harold F. Woolshlager-*

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*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  
Jill Anne Smith*

*Frances Eck-  
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*Catherine Joan Gloom-  
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*Geraldine Tocco-  
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Mary Ann Balaska  
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Robert & Vicki Squire  
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Samuel & Florence DiPrima  
Joanne Morse*

*George & Ann Marie Treen  
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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*

*CFC, SEFA, United Way, IBM, GE, Amex,  
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Exagen Diagnostics  
Walmart Stores #1677 & #2285 & #2093  
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Americu Credit Union, Commercial Drive Branch  
Presto Print, LLC  
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Rocco & Monica Falitico  
Joseph & Lori Vogel  
George P. Coutros  
Ruth VanDiver*

## *Donations*

*Helen Sarandrea, Physical Therapy  
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Bob Walseman & Isabel Woolshlager  
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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  
Lowe's of Rome  
Yahnundasis Golf Club  
Colgate University Seven Oaks Golf Club  
Betty Servatius  
AARDA  
Scott Brewster  
Jane Porter  
Bill and Sandi Frear  
Helen Cassin*





## LUPUS & AUTOIMMUNE AWARENESS AND ADVOCACY IN ACTION

