



*Our Mission: To improve the quality of life
for those affected by lupus through advocacy,
education, awareness, empowerment, and research.*

Lupus Communiqué

Lupus Foundation of Mid and Northern New York, Inc.

Volume 11, Annual Edition 2014

RECORDBREAKING RESEARCH DONATION



Lupus Research Institute Chairmen Robert Ravitz (left) and Jack lavery (right) receive our largest ever Research Donation of \$35,000 which represents a little over 1/3 of our annual income for 2013 from Lupus Foundation of Mid and NNY President/CEO Kathleen Arntsen (center) on October 7th at the LRI Annual Scientific Meeting at the New York Marriott Marquis. We are extremely proud that we have now donated \$249,500 which is a quarter of a million dollars to the LRI in the past 12 years for novel, innovative lupus research.

Lupus Foundation of Mid and Northern New York, 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 in your life while also supporting the lupus cause. If you belong to a Service or Fraternal organization, or participate in a workplace-giving program such as: SEFA, UNITED WAY, IBM 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 any address changes or other corrections to ensure accuracy in the database. If an address is incorrect the Post Office will not deliver under their revised policies and the mail piece will be returned and we will be charged a fee. 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

**The Lupus Foundation of Mid & Northern NY, Inc.
is proud to be a member of the**

- ◆ National Coalition of Autoimmune Patient Groups
- ◆ Lupus Research Institute National Coalition
- ◆ NIAMS Coalition
- ◆ Lupus Agencies of New York State
- ◆ NIAMS Lupus Federal Working Group
- ◆ NY Health Works
- ◆ New York BIO
- ◆ BIO NJ
- ◆ Health Care for all NY
- ◆ New Yorkers for Accessible Health Coverage



**Beanie Bears are available for
\$10 each
Lupus ends with US in white
Someone I Love has LUPUS in
dark brown**

The Lupus Communiqué

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Lupus Foundation of Mid and
Northern New York, Inc.*

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DISCLAIMER

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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 Lupus Foundation of Mid and Northern New York, Inc. Thank you.

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President's Message—

As the sun rises, I stare out the window at the last remnants of winter slowly melting away at the end of our driveway, hoping for inspiration to guide my fingers on the keyboard. Amber beams of sunlight suddenly burst through the glass, enveloping the room with the golden promise of a much-needed spring. It has been a tough year for many Americans due to the seemingly never ending inclement weather. Personally, the past 18 months have brought significant challenges for me to withstand. Between an auto accident, subsequent shoulder surgery, ongoing rehabilitative therapy, bi-weekly 7-hour infusions for electrolyte imbalances, a young relative's death, and lastly a severe bout of shingles on my face, scalp and in my eye during the holidays; it has been a difficult time to say the least. Like many others who are chronically ill with numerous health issues, I take pride in the fact that I am an independent, resourceful and empowered patient who navigates a convoluted health care system and the trials and tribulations of life quite well.

These new unexpected challenges forced me to take a hiatus, re-evaluate my priorities, accept my limitations, and rely on the assistance of loved ones. The situation brought back the emotions of fear, frustration, isolation, and sadness I felt when initially diagnosed with lupus decades ago. Just like then, it has also given me down time to pause, reflect and learn to be gentle with myself. I am reminded that I am not invincible and forced to let go of less important things; putting into practice my philosophy to regain control and heal. Although I am not back to pre-accident or pre-shingles condition yet, I am taking baby steps on my road to recovery; remembering to celebrate each small victory when it occurs.

As an advocate I try to provide promise and hope to those impacted by lupus and other diseases, sharing positive information as well as my own journey which although dismal at times has improved over the years. Providing encouragement by stressing research, improved awareness and being proactive in one's medical treatment are cornerstones in building a foundation to achieve a more positive prognosis. In dealing with the public misperception of lupus and autoimmunity for decades, many of us have fought tenaciously to let everyone know you can have a pretty good life if you become empowered and educated. It's easy to be a victim; it's difficult to take charge and fight. And it's ok to have bad days, we all do. Sometimes we even have bad years.

It has taken me decades to build a strong healthcare team and support system for myself and I am certainly blessed to be surrounded by resourceful, positive people who keep me and my quality of life as healthy as possible. And these relationships are reciprocal; I am thanked often by patients, loved ones and providers for sharing knowledge, positivity, hope and humor. Living with multiple autoimmune conditions and facing unexpected medical obstacles has certainly been dreadful at times and an unwelcome burden on numerous levels, but it has also brought many wonderful individuals into my circle of life. With each adversity we experience, we gain wisdom, strength and new opportunities to explore.

Since it has been over a year since our last annual newsletter I would like to share our organization overview and accomplishments with you. In September the Board of Directors voted to make changes within the organization to continue to provide the most optimal services we can to the community given our geographic location, the poor economy, inclement weather, and less demand for patient outreach services. We also understand that many of you are just as busy as we are in this complicated, multi-tasking, overwhelming world which makes it difficult to attend support and education meetings in person. We realize that people connect today instead through an abundance of technological and social platforms. After retaining the services of a non-profit lawyer and performing a thorough evaluation the Board voted to transition the organization to build on our strengths and focus more on public education, advocacy and research programs and collaborate with other health care stakeholders on these initiatives.

Advocacy has been and will continue to be a major part of our program services. We not only advocate for people affected by lupus and other autoimmune diseases but also for health care reform and patient access to care issues which affect each and every American including: the ACA implementation, protecting Medicare and Medicaid programs, ensuring strong patient protections exist, supporting NIH and biomedical research programs, commenting on FDA guidance for Biosimilars and other relevant issues, and advancing health information technology. We are passionately committed to ensuring that all Americans receive the most appropriate therapies as directed by their providers and that drug development and discoveries continue to progress rapidly to improve quality of life.

We are also expanding our collaborative efforts with other biopharmaceutical stakeholders to promote patient-centered care and to ensure public policy keeps pace with biomedical research innovation. Drug research and development needs to be encouraged and supported and not stifled by bureaucracies so that all individuals, regardless of race or socioeconomic status can live longer and healthier lives. As long as our health care system remains imperfect and unequal, advocates like us will continue to raise our voices in objection. If we can change the policies of a single clinic, hospital, doctor's office, pharmacy, insurance company, health plan administrator, legislator, or government agency official then our efforts are worthwhile. If you have a personal story about a health care access issue that has impacted you or someone you love then please share it with us.

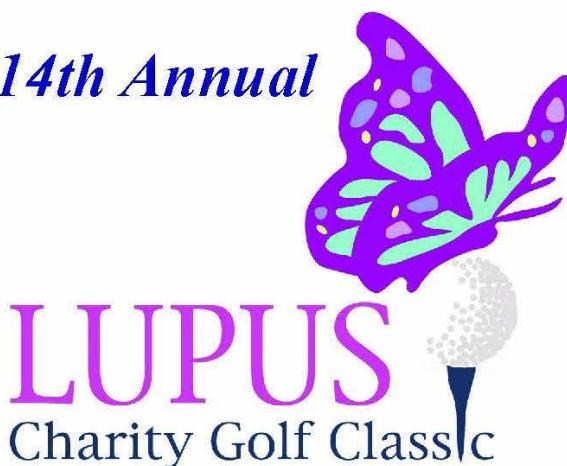
In May we were the lead NYS Lupus Agency running the 5th Annual Awareness Day in the State Capital and the Lupus Exhibit at the NYS Fair in late summer and we have continued to promote our "The Power of Advocacy—Promoting Participation to Improve Care" an informative presentation on how to become an effective personal and public advocate with an overview of current access and health policy initiatives and "Hope is on the Horizon" program to educate consumers on the importance of clinical research trials in getting new treatments to patients. Our community education programs are designed to empower people to become more proactive in their own health care and to become engaged in the public policy process. We are also collaborating on national health disparity and autoimmune awareness initiatives as well.

2013 was another record breaking year for the annual Golf Classic proceeds and our research donation to the Lupus Research Institute. Although the local economic forecast has not improved our supporters have remained steadfast and generous far beyond our expectations. On a much broader scale it has been a remarkable year of progress for all in the lupus and autoimmune communities. Innovative translational research and development initiatives that include collaborative stakeholder partnerships are taking place that give us hope that safer, more effective therapies and cures are just around the corner. Meaningful partnerships between government agencies, patient advocacy and professional organizations, academia, the medical community, research entities, and the biopharmaceutical industry have emerged. Bearing witness to these achievements has brought a sense of pride and fulfillment to those of us who have pushed for these endeavors for years.

We are certainly grateful for the accomplishments of the past year and continuously amazed by the dedication of all in the lupus and autoimmune communities. It is only through our united efforts that we can move forward and succeed in the battle against lupus and other diseases of unmet need. Finally there is hope on the horizon for those affected from a multitude of sources that are connected by this cause. We at The Lupus Foundation of Mid and Northern New York are proud to play a small, but active role and honored to represent you during these thrilling times. We have high expectations for a year filled with tremendous promise and progress into the diagnosis, treatment, and research of Lupus Erythematosus. We are extremely thankful for your continuing support; afterall, Lupus ends with US!

Enjoy the Spring Weather and Be Well—Kathleen

14th Annual



**Shenandoah Golf Course
at
Turning Stone Resort**

Thursday, August 21, 2014

Proceeds Benefit The:

**LUPUS FOUNDATION
of Mid and Northern New York, 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 18th \$175 per golfer

Registration after July 18th \$200 per golfer

Sponsorship Opportunities Available



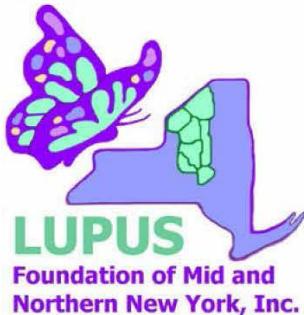
**Help to Make a Difference for those Affected by Lupus
While enjoying a great round of golf**

**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 lupusmidny@aol.com

or visit our website www.nolupus.org



**FOURTEENTH ANNUAL
LUPUS CHARITY GOLF CLASSIC**
AUGUST 21, 2014
Shenendoah Golf Course
Turning Stone Resort Casino



SPONSORSHIP FORM

Corp. Name: _____

Attention: _____

Address: _____

City/ State/ Zip: _____

Phone: _____ E-mail: _____

- \$10,000 EVENT Sponsor** – Complimentary Foursome, logo display on event & promotional materials, dinner tables, carts, banner display, tee sign, program listing, dinner recognition
- \$6,000 DIAMOND Sponsor** – Complimentary Foursome, logo display on event, dinner tables, carts, banner display, tee sign, program listing, dinner recognition
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- \$500 GOLD Sponsor** **\$250 SILVER Sponsor** **\$100 BRONZE Sponsor**
Tee sign, program listing
- Other Donation** – Please list _____

* All foursomes include 18 holes of golf w/cart, lunch, and dinner for four

For additional information call: 315-829-4272 or 1-866-2-LUPUS-4 or E-mail lupusmidny@aol.com

Please make checks payable to: *The Lupus Foundation P.O. Box 139 Utica, NY 13503*

EDUCATION & RESEARCH



AWARENESS & ADVOCACY



**Alliance for Lupus Research and Lupus Research Institute
Partner with National Institutes of Health
to Accelerate Drug Discovery in Lupus**

*Lupus Research Organizations Welcome Big Science Push
to Drive New Therapies for Lupus Patients*

February 4, 2014

We are delighted to share that the **Alliance for Lupus Research (ALR)** and the **Lupus Research Institute (LRI)** have joined the National Institutes of Health (NIH) and industry in the [Accelerating Medicines Partnership \(AMP\)](#) launched today to speed new paths to treatment for [lupus and autoimmune diseases](#).

Recognizing that no new targeted therapies exist for severe lupus, the new consortia will work to better understand the disease and uncover new targets for drug development. A total of \$41.6 million is allocated specifically to the [autoimmune diseases](#) lupus and rheumatoid arthritis. As members of the consortia steering committee for lupus and rheumatoid arthritis, LRI and ALR will have an active role in setting the research agenda and assessing progress. You may have heard about the AMP in today's news with significant coverage by the [Wall Street Journal](#), [Washington Post](#), and other major media outlets signaling its importance and magnitude.

Collaboration Pushes Discovery Forward

"We are very pleased to see the NIH build upon the deep foundation of novel scientific discovery that the lupus research organizations have accomplished over the past decade," said Margaret Dowd, President and CEO of the Lupus Research Institute. "By investing in early-stage, high-risk ideas, we have supported fundamental understanding of the disease, successfully identifying a diverse range of new pathways and targets in lupus. Those breakthroughs all along the research continuum are what allow us to drive to clinical studies."

Alliance for Lupus Research President Kenneth M. Farber commented, "The large-scale approach of the AMP program is necessary to critically assess which of the many novel pathways and targets implicated in lupus show the greatest promise for the development of new therapeutics. We are excited to be part of this new consortia that takes collaboration in lupus to a new level. By advancing targets, the program promises to benefit not just lupus patients but all those living with systemic autoimmune diseases."

ALR and LRI Foster Collaboration

ALR and LRI regularly bring the lupus community and industry together, as part of our efforts to advance lupus research and new drug development. In addition to contributing to the AMP program, the two organizations recently initiated a [trailblazing cooperative project](#) to speed up the identification and availability of new treatments for lupus.

"We are very pleased to again join with the ALR in this unprecedented collaboration with the wider research community to bring patients safer and more effective treatments faster."

ALR-LRI Collaboration to Accelerate New Lupus Treatments Moving at Fast Pace

155 Potential Lupus Therapies Identified for Further Analysis

February 26, 2014

The Alliance for Lupus Research (ALR) and the Lupus Research Institute (LRI) are excited to report rapid progress on the cooperative project we launched just months ago to fast-track scientific analysis and identification of potential new treatments for lupus. The lupus community participates with comments, ideas and input on the program's dedicated [LinkedIn site, LRxL STAT.](#)

The proactive initiative focuses on identifying new treatments from among those that are approved for other conditions. We are encouraged that progress has been even more rapid and comprehensive than anticipated with 155 potential therapies analyzed and identified from an initial analysis of 6,800 therapies approved for human use. A prestigious expert committee will soon review these results and prioritize the best candidates for clinical trials in lupus.

Developer of scientific content, Amrie Grammer, PhD comments, “We are very grateful to the entire lupus community for helping us to identify candidate drugs and treatments for re-positioning into lupus based on mechanism of action, safety profile and feasibility for testing. After the list is prioritized, the goal is to conduct small, science-rich, proof-of-concept trials as the shortest path to new treatments.”

LRI CEO Peggy Dowd notes, “The number of drugs with potential for use in lupus is extremely encouraging, and we look forward to identifying the drugs and treatments which hold the greatest promise to improve patient care. This partnership has moved the lupus field forward in a way we have never seen before.”

“We are very excited at the rapid progress of the joint initiative of ALR and LRI,” says ALR President Kenneth M. Farber. “It is very promising that there are so many drugs and therapies that are intriguing candidates to be repositioned for lupus. We look forward to the opportunity to test as many of these candidates as we can. Developing safer, more effective therapies for lupus patients is our highest priority.”

Moving on Several Fronts

In addition to this project, the ALR and LRI are also funding members of the [Accelerating Medicines Partnership \(AMP\)](#) launched earlier this month by the National Institutes of Health to understand the molecular pathways underlying lupus. It is hoped that AMP will identify additional pathways that can be targeted with novel therapies for lupus.

Commitment to Developing New Therapies

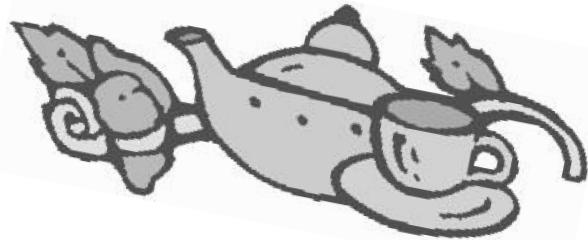
Both the LRI and the ALR are committed together and individually to supporting initiatives that can bring lupus patients the safer and more effective treatments they need and deserve, both immediately (LRxL STAT) and in the longer term (AMP).

An Invitation to Celebrate World Lupus Day

WHAT: Victorian Tea

WHERE: Your Home

WHEN: May 1, 2014



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 Lupus 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 Foundation
PO Box 139
Utica, New York 13503***



Thank you for your Consideration and Support!!!

The Lupus Foundation of Mid and Northern New York, 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 lupusmidny@aol.com.

Memorials, Tributes, and Donations

Memorials

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Bob & Cathy Walseman

Isabel Woolshlager

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Larry & Karen Woolshlager & Family

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Jack & Marcia Flint & Family

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Joseph & Mary Turck

Bob & Cathy Walseman

Gary & Deborah Walseman

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Rosemary Gerace

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Palma "Pam" La Bella

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*Joseph Jupin-
Victoria Jupin*

*Bonnie J. Martin-
Kay J. Falcone*

*Oscar McLain-
Ellen C. Gloo*

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In Loving Memory of...

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Louis A. Relf
Sam Relf
Elva Fox
Arthur A. Relf
John & Alberta Bagley
Elmer & Alice Bagley-
James & Patricia Mitchell
David & Kathleen Arntsen*

*James E. Mitchell
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Harold Leach
Catherine Leach
James E. Mitchell
Elizabeth Mitchell
Thomas P. Mitchell-
James & Patricia Mitchell
David & Kathleen Arntsen*

*Isabell Zeock-
John Zeock*

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

*Elwood Virkler-
Jeffrey & Susan Virkler & Family*

*Anita Curtiss-
Larry & Karen Woolshlager & Family*

*Jim, Mary Alice & Tom Mitchell-
Jane Williams*

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

*Angelo J. "Joe" Marotta-
Frank & Lyn Soja*

*Bernice Birnbaum-
Irene Fried*

Memorials, Tributes, and Donations

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The Mitchell Family
Utica Professional Fire Fighters IAFF Local 32
Walmart Stores #1677 & #2285
Family & Friends of Geri Lemke
David & Kathleen Arntsen
Buyer of Gold & Silver/Teague Accounting Xperts
UFCW District Union Local ONE
Americu Credit Union, Commercial Drive Branch
Ellen Gloo
Presto Print, LLC
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Raquel Rosen, MD
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NYS Assemblymember Anthony Brindisi
Rocco & Monica Falitico in Honor of Roxanne
Rick & Kathryn Voskuil
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Gates-Cole Insurance
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Edward B. Lee, MD
Tony & Anna Maria Maritato
MCORP—Dan & Lisa Mitchell
NY State Iron Workers
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Tributes

In Loving Honor of...

Geri Lemke-
Friends & Family
Virginia Merola

Rocco & Monica Falitico-
Virginia Merola

David Arntsen's Birthday-
James & Patricia Mitchell

Kathleen Arntsen's Birthday-
James & Patricia Mitchell

Monica & Rocco Falitico-
Virginia Merola

Patricia Mitchell's Birthday-
David & Kathleen Arntsen

James Mitchell's Birthday-
David & Kathleen Arntsen

James & Patricia Mitchell,
Dan & Lisa Mitchell,
Dan & Lois Rumfelt,
For Christmas-
David & Kathleen Arntsen

World Lupus Day Tea
David & Kathleen Arntsen
Rocco & Monica Falitico
Cynthia Donaldson
Tom & Jackie Taylor
Larry & Kathy Scharf
Bill & Sandi Frear
John Porter & Elisabeth Kaye
Robert & Jennifer Porter
James & Patricia Mitchell
Carol Walker
Victoria Jupin
Norman & Arlene Stanulevich
Phil & Kathy Teague
Jaime Venditti
Ellen Gloo

Frank & Stephanie Darwak
Dale & Maryrose Bullock
Jill Anne Smith
Julie Miner
Jane Williams

13th ANNUAL LUPUS CHARITY GOLF CLASSIC



What a day to break a record! The 13th Annual Lupus Charity Golf Classic was held on August 8th, 2013 -- a cloudy morning that turned into a perfect Friday afternoon at Shenendoah Golf Club at Turning Stone Resort in Verona, NY. More than \$53,000 net and a new fundraising record was raised to fund our program services. Thank you to all of the golfers, sponsors, volunteers, and supporters who made the event possible.

