# CENTRAL NEW YORK LYME & TICK-BORNE DISEASE ALLIANCE



#### **GROWTH & PROGRESS**

## Two words succinctly capture the work of the CNY Lyme & Tick-Borne Disease Alliance – "Growth" and "Progress."

As I begin my new role as Chair of the Board, I am honored and grateful to build upon the vision and leadership of Anne Messenger, Founding Chair, Royale Scuderi, Executive Director, and our incredibly committed board members.

We began a mere four years ago knowing that we were on the cusp of a health care crisis and needed to bring together researchers, clinicians and Lyme and other tick-borne disease patients and prevention experts. It was then that we learned "no one was doing it like this in the country," according to Scott Santorella, former Executive Director of the Global Lyme Alliance.

We haven't taken that comment lightly, and have moved at a feverish pace to raise awareness, drive education and offer support to those affected by Lyme disease. You will see in this report that much has been done. There is still so much more to do, and we need your support, your energy and your commitment.

#### How can you help? Easy ~

- Learn about Lyme visit our website often (cnylymealliance.org)
- Help spread the word follow us on social media and share our content
- Donate to our organization easy to do on the website
- Join us at the Legs Against Lyme Walk on June 1
- Follow us at the Lyme Summit 2024
- Invite our educators to your work or community groups
- Join or refer Lyme patients to our support group
- Volunteer to help raise awareness

#### **Growth and Progress!**

I guarantee that after reading this report, you will respond as one of our newest board members did — "Wow, so much accomplished. Go Team!"

Danielle Cummings

Danielle E. Gemmings

Board Chair

#### Look how far we've come in a few short years with your support

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In 2020, we started with 0 staff members; in 2023, we added another FT Educator + PT Development Coordinator, bringing us to 4 staff, a PT communications consultant and 5 education volunteers.



In 2020, during COVID, we conducted 18 events for 531 individuals. We've experienced so much growth since, that in 2023, Lyme Alliance staff and volunteers conducted 71 events and provided hands-on education for 7,500 individuals.



From 2020-2023, we have distributed a combined total of 17,000 copies of our English/Spanish educational handout throughout our three-county region with the help of area businesses, nonprofits and community partners.



In 2021, we met with elected officials and started building relationships: in 2022, we advocated for awareness and funding, receiving an award of \$68.000 in NYS funding. In 2023, we continued to expand our advocacy efforts with a resulting \$50.000 NYS award and a \$75.000 award from Onondaga County to continue our crucial work.



In 2021, we started a summer camp program for 500 children in Onondaga County, and by 2023, we expanded our youth education program to 2,500 youths in three counties.



In 2021, we designed and distributed 500 tick kits, and in 2023 we improved our tick kit design and distributed 2,500 tick kits plus added 1,000 youth bags and flashlights for our young participants in our youth education program.



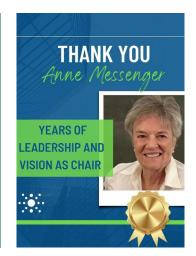
In 2022, we held our first-ever Lyme Summit with 50 attendees. In 2023 we held our second Lyme Summit here in Syracuse with nationally recognized speakers to provide education for healthcare providers with 131 attendees.



In 2023, we held our second annual successful Legs Against Lyme Walk with nearly 200 registrants and a 60% increase in funds raised.



In 2023, we continued to increase visibility and awareness with interviews, PSAs, an expanded social media following, increasing website visitors and multiple billboards in more locations with more than 1 million impressions annually.





#### **SECOND ANNUAL LYME SUMMIT**

### 2023 LYME & TICK-BORNE DISEASE SUMMIT GROWTH

We were thrilled to have had a full house at our Second Annual Lyme Summit on September 28 and 29, 2023, here in Syracuse with nationally recognized speakers to provide education for healthcare providers. We were joined by 131 attendees, scientists, doctors, physician assistants, nurse practitioners, veterinarians, funders, patients and more. So much listening, so many conversations, so much learning!

cnylymealliance.org/lymesummit









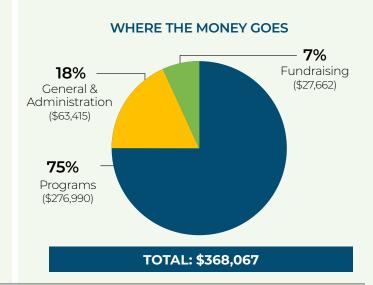
#### **SECOND ANNUAL LEGS AGAINST LYME WALK**

On May 13, 2023, we gathered with Central New York's Lyme Warriors for the second Annual Legs Against Lyme Walk at Long Branch Park! With the leadership of Legs Against Lyme Walk Chair Nicole Sommavilla, this year's walk was another extraordinary, tick-free event!



#### **2023 FINANCIALS**

#### WHERE THE MONEY COMES FROM 20% - 1% General Misc. Income **Donations** (\$3,704) (\$77,496) 25% Government 54% **Awards** Foundations & (\$100,000) Grants (\$212,750)TOTAL: \$393,950



#### **CONTRIBUTIONS IN 2023**

#### **Foundation Support**

Dorothy and Marshall Reisman Foundation

Frank and Frances Revoir Foundation

Kinney Drugs Foundation

Mother Cabrini Health Foundation Richard S. Shineman Foundation Rose Family Foundation



#### **Corporate Support**

Dannible & McKee, LLP

Excellus BlueCross BlueShield

Insect Shield

KeyBank

Kinney Drugs

Northland Communications

Pinckney Hugo Group

Ranger Ready

SUNY Upstate Institute for

Global Health

Velocity Clinical Research

Warne/McKenna Advertising

Wegmans

#### Gifts of \$1,000+

Fatme Allam, MD

Eric Allyn &

Meg O'Connell

Catherine Bertini

J. Andrew Breuer

Julie Colvin, MD

Barbara Connor, MD

Elizabeth Etoll

Kristin Gamble

Christine Herb

Michela Hugo

Zalie & Bob Linn

Ryan Maness &

Virgie Townsend

#### Gifts of \$500+ .....

Carla Nielson

#### Gifts of \$100+

Advocates Incorporated

Darlene Babcock

Danielle Cummings Molly Cummings

William Evans

Tyler Forbes

Nassib Habayeb

William Kinne

Pat Lamb

Carly Mayenzet

Emilija Postolovska

Patrick Riccardi

M. Catherine Richardson

Michelle Saya

Anne Messenger

The Pinckney Family

Douglas Wojcik, DVM

Royale Scuderi

Kathy Slattery

Saravanan Thangamani, PhD

Stephen J. Thomas, MD

Kristopher Paolino, MD

Jackie Vercillo

James Wright

Douglas Wood

#### **LEADERSHIP TEAM**



Fatme Allam, MD Clinical Associate Professor of Medicine/Rheumatology, Upstate Medical University, Chief of Rheumatology, Syracuse VA Medical Center



Elizabeth Balfour Education Coordinator, CNY Lyme & Tick-Borne Disease Alliance



**Julie Colvin, MD** Family Medicine, St. Joseph's Physicians



Danielle Cummings Board Chair Chancellor, Roman Catholic Diocese of Syracuse



**Jonah Cummings** Educator



Nicole Fragnito
Development Coordinator



Joseph Hardick, CPA, CCIF Board Treasurer Tax Partner, Dannible & McKee



**Michael Jennings II**Wealth Consultant,
Brackens Financial
Solutions Network



Wesley D. Kufel, PharmD, BCIDP, BCPS, AAHIVP Chair, Governance Committee Clinical Assistant Professor of Pharmacy Practice, SUNY Binghamton School of Pharmacy



Shantina Hines Kyles Board Secretary Spinal Cord Injury Manager



**Brian Leydet, MPH, PhD** Assistant Professor, SUNY College of Environmental Science and Forestry (ESF)



**Ryan Maness**Director and Counsel, Tax
Policy, MultiState Associates



**Anne Messenger** Chapter Chair, Women Presidents' Organization



Kristopher Paolino, MD, MTM&H, FACP Board Medical Director Assistant Professor of Medicine; Assistant Professor of Microbiology and Immunology, SUNY Upstate Medical University



Georgina Pinckney Chair, Development Committee Tick-Borne Disease Advocate



Emilija Postolovska, MPH Director of Workforce Innovation, CenterState CEO



**Elizabeth Ruscitto**Private Consultant



Michelle Saya, RN, BSN, MSM VP of Compliance, Kur Research



Royale Scuderi Executive Director, CNY Lyme & Tick-Borne Disease Alliance



Simone Seward, MPH, PhD Board Vice Chair Director, Health Equity Research and Programs Director, Center for Civic Engagement, SUNY Upstate Medical University



Saravanan Thangamani, PhD Director, Vector Biology Laboratories, SUNY Upstate Medical University; Department of Microbiology and Immunology, Director, SUNY Center for Environmental Health and Medicine



**Douglas E. Wojcik, DVM** Owner, Liverpool Animal Hospital





#### **WHAT'S NEXT?**

#### We have a long to-do list for 2024. At the top:

1.

Increase community awareness and engagement

to address differing needs of diverse communities throughout our region. 2.

**Grow our youth education program** to include a K-12
curriculum in area schools.
When you teach a child,
you teach a generation.

3.

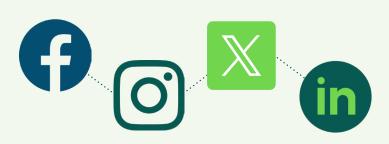
Expand our provider education program beyond the annual Lyme Summit to include medical students and provider education year-round.

#### **HOW TO BECOME INVOLVED**

There are many ways to support the work of the Central New York Lyme & Tick-Borne Disease Alliance. Visit **cnylymealliance.org** to find out how you can help today.

We're adapted for life in a virtual world!

Please follow us on social media!



#### **ACKNOWLEDGEMENTS AND PROFOUND THANKS**

When it comes to progress, we send our most grateful thanks to those who've stuck with us! We are ever grateful to our donors, community partners, legislators, media and volunteers. We are encouraged by the groundswell of public support — calls, questions, ideas and stories. They remind us, every day, of the challenges facing our community and the urgency of our work.

#### Thank you!

