



CENTRAL NEW YORK
LYME & TICK-BORNE
DISEASE ALLIANCE





EDUCATE. ENERGIZE.

We are agreed. Patience is not our forte. Tick-borne disease is on an alarmingly swift rise, and we are determined to combat it.

We are realistic about the challenge, though. And driven. That's an interesting combination, leading us to the dual themes of this annual report: **Educate. Energize.**

Joining us in educating are our deeply engaged board members and a host of community partners. Even when we had to COVID-pivot from in-person classes, Central New Yorkers joined us in full force on Zoom, with questions and stories galore. The YMCA of Central New York welcomed our pilot program into Camp Evergreen for a series of presentations to enthusiastic campers and we heard from grateful parents afterward, with one immediate text showing a daughter triumphantly holding up her new tick kit, to another comment from a job applicant almost a year later. We are energized.

Our education continues, and it's a two-way street. Patients contact us, especially those with so-called "chronic Lyme" — life-changing, life-threatening symptoms hanging on for years, sometimes decades. Still with no silver bullet answers to their questions, we deeply appreciate and feel the pain of their stories, and their help in spreading the word significantly broadens our educational reach.

Hundreds of thousands of people have engaged in our social media posts and conversations and seen and responded to our billboards and public service announcements.

We still have much work to do, and we can't do it alone. We are so grateful for the help from all sides. Thank you, Central New York! We are energized!

Anne Messenger,
Board Chair

Royale Scuderi,
Executive Director



OUR PURPOSE

The CNY Lyme and Tick-Borne Disease Alliance is a collaborative of providers, scientists and community members who **support research, drive education** and **promote awareness** to combat tick-borne diseases.

CENTRAL NEW YORK HAS A PROBLEM. A BIG ONE.

Central New York, an epicenter of Lyme and tick-borne disease, is at the edge of a health crisis.

It's logical for CNY to be the epicenter of research and treatment as well. For years, patients and families have spent time, energy and money going hours/miles away for help, many times with few, if any, positive outcomes. Underserved persons have been disproportionately affected to a significant degree.



TELLING THE STORY. IT'S URGENT. IT'S PERSONAL.

Community members have shared the profound challenges of living with Lyme. Their experiences keep us on task. We are grateful for their courage in telling their stories.

WE WANT TO HEAR FROM YOU!

Meet Nicole
Infected with Lyme disease in 2013, but never diagnosed until 2017, Nicole is working hard to stay in "remission."
My challenges with Lyme disease include:
• ANXIETY
• BRAIN FOG
• DAILY FATIGUE
"Wherever you are in your Lyme struggle, it can always get better!"
STORIES

We want to hear from YOU!
We're looking for Central New Yorkers impacted by Lyme and tick-borne disease to share their stories with us.
ROYALE SCUDERI CHOL MAJOR MISTY RANGEL
Learn more on our website!

Meet Jonah
With infection and diagnosis in 2017, Jonah is making progress in taking control of his life despite Lyme disease.
My challenges with Lyme disease include:
• BRAIN FOG
• CHEST PAIN
• GI ISSUES
"If you are suffering from Lyme or co-infections, be your best advocate!"
STORIES



TWO YEARS UNDER OUR BELTS

View the story at: <https://cnylymealliance.org/twoyears>

“COVID is eventually going away.
Ticks are here to stay.”

- Stephen J. Thomas, MD, Alliance Board Member and
Director of the Institute for Global Health and Translational Sciences

WHAT WE'VE DONE IN 2021



Conducted education and information sessions for 1,220 attendees from a broad range of audiences in Madison, Onondaga and Oswego counties.

Developed a summer camp program and distributed tick kits to 500 summer campers and staff at the YMCA's Camp Evergreen in Onondaga County and the YMCA in Madison County.

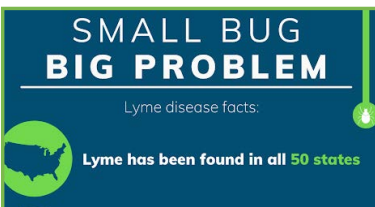


Distributed nearly 7,000 copies of our English/Spanish educational handout throughout our three-county region with the help of area businesses, nonprofits and community partners.



Substantially increased our visibility and awareness through 10 TV and radio interviews, developed PSA spots with a total of 786,000 impressions, expanded social media following to 4,000+, received more than 1,000 website visitors a month and placed billboards in 3 counties.

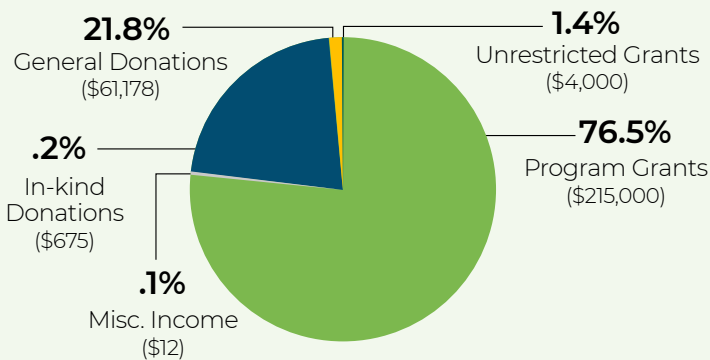
Met with numerous CNY elected officials and the Onondaga HHS Committee and held a joint legislative public event with NYS Assemblymember Didi Barrett, Dr. Kristopher Paolino and Dr. Richard Horowitz.



Held an online art auction and fundraising campaign in May, raising more than \$50,000 in donations.

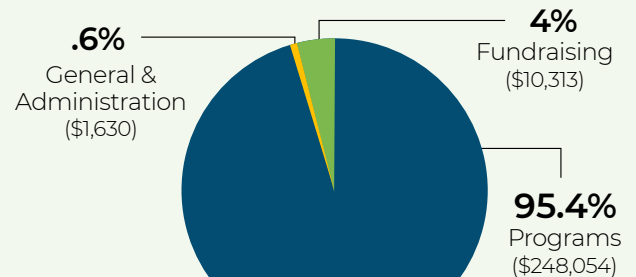
FINANCIALS TO DATE

WHERE THE MONEY COMES FROM



TOTAL: \$280,865

WHERE THE MONEY GOES



TOTAL: \$259,997

CONTRIBUTIONS IN 2021



*Thank you to our
donors for their
generous support!*

Foundation Support

Central New York Community Foundation
Frank and Frances Revoir Foundation
Mother Cabrini Health Foundation
Richard S. Shineman Foundation

Corporate Support

Excellus BlueCross BlueShield
Medical Weight Loss of N.Y.
Ranger Ready
Warne-McKenna Advertising
Wegmans

Gifts of \$1,000+

Eric Allyn and Meg O'Connell
Aminy Audi
Kristin Gamble
Zalie and Bob Linn
Anne Messenger
The Pinckney Family

Gifts of \$500+

Catherine Bertini
Kathryn Clarke
Barbara Connor
Elizabeth Etoll
Kathy and Dan Ruscitto

Gifts of \$100+

Danielle Cummings
Bill Fisher
Colleen Pleasant Kline

Shantina Hines Kyles
Claudia Lusby
Carla Nielson

Kristopher Paolino, MD
Simone Seward
Kathy Slattery

Stephen J. Thomas, MD

LEADERSHIP TEAM



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



Barbara Connor, MD
Cayuga County Staff
Physician and
Sub-Investigator
Velocity Clinical Research



Danielle Cummings
Co-Vice Chair,
Chair Communications
Chancellor,
Roman Catholic
Diocese of Syracuse



Michael Jennings II
Business Development
Associate, Financial
Planning



**Wes Kufel, PharmD,
BCIDP**
Chair, Governance
Clinical Assistant Professor,
Pharmacy Practice SUNY
Binghamton School of
Pharmacy



Shantina Hines Kyles
Secretary
Spinal Cord Injury Manager



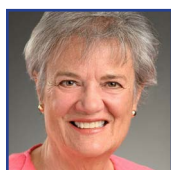
**Brian Leydet, MPH,
PhD**
Assistant Professor, SUNY
College of Environmental
Science and Forestry (ESF)



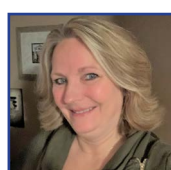
Zalie Linn
Treasurer,
Chair, Finance
Retired Financial Consultant



Ryan Maness
Director and Counsel, Tax Policy



Anne Messenger
Chair
Chapter Chair Women
Presidents' Organization



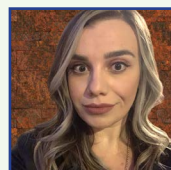
Christine Paul
Executive Director for the
Madison County Rural
Health Council and
Mental Health First Aid
(MHFA) Instructor



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



Georgina Pinckney
Chair, Development
Committee
Tick-Borne
Disease Advocate



Emilija Postolovska, MPH
Senior Analyst, Public Health



Kathryn Ruscitto
Co-Vice Chair
Board Member and Advisor



**Michelle Saya, RN, BSN,
MSM**
Clinical Research
Compliance Specialist,
SUNY Upstate Medical
University



Simone Seward, MPH
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



Stephen J. Thomas, MD
Chair (interim), Department of
Microbiology & Immunology,
SUNY Upstate Medical University
and Director, Institute for
Global Health and
Translational Sciences



Douglas E. Wojcik, DVM
Owner, Liverpool Animal Hospital

WHAT'S NEXT?

We have a long to-do list for 2022. Three items at the top:

1.



Increase
community engagement
to address differing needs
of our communities.

2.



Expand
our education program
and hire a full-time
Education Coordinator.

3.



Explore
additional partnerships
to increase collaboration and
improve outreach efforts.

HOW TO BECOME INVOLVED

There are many ways to support the work of the Central New York Lyme & Tick-Borne Disease Alliance. Visit www.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

We are grateful to our donors, community partners, legislators, media and volunteers. We are very encouraged by the groundswell of public support — calls, questions, ideas and, again, stories. They remind us, every day, of the challenges facing our community and the urgency of our work.

Thank you!

