ANNUAL REPORT | 2020

CENTRAL NEW YORK LYME & TICK-BORNE DISEASE ALLIANCE





BOARD CHAIR THOUGHTS

Two years ago, Central New York faced a tough health challenge and a terrible irony.

The Challenge:

Swiftly growing incidence of Lyme and tick-borne disease.

The Irony:

Multiple, excellent resources to combat the threat, but little, if any, coordination of effort. In a word, silos.

Who Suffered Most:

Patients, especially those with so-called "Chronic Lyme" — life-changing, life-threatening symptoms hanging on for years, sometimes decades.

It was complicated, but really so simple. We needed answers. And we needed a 1+1 = 3, collaborative approach to finding them.

Fast-forward to today: We face the same tough threat presented by ticks, but silos are disappearing as we connect dots. Doctors, nurses, scientists and community members sit on our board and work together behind the scenes between monthly meetings. Thousands of people engage in our social media posts and conversations. Elected officials have us on their screens. Perplexities of the multiple diseases persist, but we're tackling them with a rock star team intent on finding answers. "No one is doing it like this in the country," we've been told by Scott Santarella, former CEO of the <u>Global Lyme Alliance</u>.

Please read on. This is our first "annual" report, covering a little more than our start-up year of operation. We've had a lot of help from a lot of people, to whom we're deeply grateful. We're on our way.

Anne Messenger

Anne Messenger, Board Chair



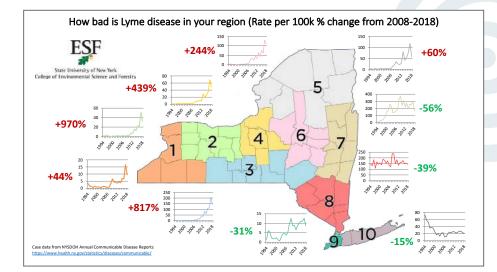
OUR PURPOSE

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 and miles away for help, many times with little, if any, positive outcomes. Underserved persons have been disproportionately affected to a significant degree.



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

Friends have shared the profound challenges of living with Lyme disease. Their experiences keep us on task. We're grateful for their courage in telling their stories.

View the story at: cnylymealliance.org/lyme-stories



WE'VE EVOLVED FROM CONCEPT TO ORGANIZATION



WHAT WE'VE DONE IN ONE SHORT YEAR, FROM START-UP TO OPERATIONAL

We're in the business of dissolving silos and connecting dots. "Collaboration" is the name of our game. *It's our differentiator*.

No one is doing it like this in the country.

- Scott Santarella, former CEO of the Global Lyme Alliance

Along the way, the cross-functional Alliance has been intensely focused on finding effective, evidencebased answers to questions that fall within four foundational pillars – **Clinical/Clinical Research, Education, Research, Environment.**

CLINICAL/CLINICAL RESEARCH	EDUCATION
 What are the best treatments for Lyme disease and post-treatment Lyme syndrome? Are there differences in how medical providers care for people with Lyme and other tick-borne diseases? Is it possible to predict who may have a more severe case of Lyme disease and require expanded treatment plans? 	 How do we best educate students and medical providers on how to recognize, diagnose and treat Lyme and other tick-borne diseases? What are the best methods available to educate a diverse community about Lyme and tick-borne diseases? How do we ensure equal access to prompt and proper treatment for Lyme and other tick-borne diseases?
BOARD OF	DIRECTORS
RESEARCH	ENVIRONMENT
• How often are ticks infected with more than one bacteria or	Are there new tick species being introduced into CNY? If

- virus and how efficiently can they pass multiple organisms to a human?
- What are the associations between a person's immune response to infection with Lyme or other tick-borne diseases and the severity and duration of the sickness?
- Is it possible to develop a vaccine or drug to protect against or more effectively treat Lyme and other tick-borne diseases?
- Are there new tick species being introduced into CNY? If so, are they carrying organisms that could cause disease in humans?
- Is it possible to develop novel prevention methods to protect people against exposure to ticks?
- Why are ticks becoming increasingly prevalent in CNY and is there anything we can do about it?

FINANCIALS TO DATE



Assembled a team:

•Board •Board Officers •Executive Director

Adopted a name, bylaws and governance policies and incorporated and attained 501(c)(3) status.





Adopted four operational pillars:

•Clinical/Clinical Research, Education, Research and Environment

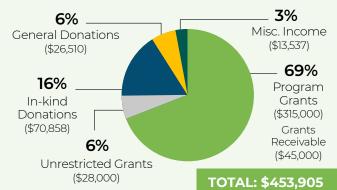
Developed a track to the Upstate Medical University's Tick and Mosquito-Borne Diseases Laboratory for free tick tests: <u>https://nyticks.org</u>.

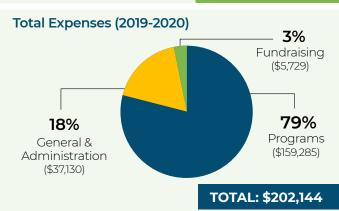
Received funds from seven foundations: •Allyn, CNYCF, Gifford, Mother Cabrini Health, Revoir, Reisman and Shineman

Held education sessions for a broad range of audiences, including community engagement professionals, garden clubs, Girl Scouts and its leaders, community organizations, Rotary clubs, Thursday Morning Roundtable and neighborhoods.

Met with county health departments and local and state elected officials.

Total Revenue and Support (2019-2020)





CONTRIBUTIONS TO DATE



Foundation Support

Allyn Family Foundation Central New York Community Foundation Frank and Frances Revoir Foundation Mother Cabrini Health Foundation Richard S. Shineman Foundation The Gifford Foundation The Dorothy and Marshall M. Reisman Foundation

Corporate Support

Bond, Schoeneck & King Business Document Solutions, Inc. Byrne Dairy, Inc. Pinckney Hugo Group

Gifts of \$500+

Carolyn A. Fischi Brian Leydet Sr. Margaret O'Connell Robert Weisenthal, MD Women Presidents' Organization, Platinum V Chapter

Gifts of \$1,000+

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Gifts of \$100+

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M. Catherine Richardson Maria Russell Royale Scuderi Nan Strickland Saravanan Thangamani, PhD

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Royale Scuderi Executive Director



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Assistant Professor of Medicine

Board Medical Director

and Assistant Professor of Microbiology and Immunology, SUNY Upstate Medical University

Kathryn Ruscitto

Co-Vice Chair



Shantina Hines Kyles **Registered Nurse**



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Zalie Linn Treasurer Chair, Finance

MTM&H, FACP



Anne Messenger Chair Chapter Chair Women Presidents' Organization



Meg O'Connell Member, Governance Executive Director. Allyn Foundation



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Saravanan Thangamani, PhD



Stephen J. Thomas, MD Vice Chair

Chief. Division of Infectious Diseases/Director. Institute for Global Health and Translational Science Infectious Disease Associates



Simone Seward, MPH Chair, Governance Director, Civic Engagement, SUNY Upstate Medical University



SUNY Empire Innovation Professor, Department of Microbiology and Immunology; Director, SUNY Center for Environmental Health and Medicine; Director, Vector **Biology Laboratories SUNY** Upstate Medical University

WHAT'S NEXT?

We have a long to-do list for 2021. Three items at the top:



HOW TO BECOME INVOLVED

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



ACKNOWLEDGEMENTS AND PROFOUND THANKS

We're pleased to have had the guidance and support of the Global Lyme Alliance in helping CNY launch an effort to research, educate, treat and advocate for Lyme and tick-borne diseases. We emerged from its fiscal sponsorship in 2020, but it continues to be a strong collaborative partner. We greatly value its support and are proud to participate in the GLA Lyme Education Ambassador Program.

A 2020 sampling:

We would also like to thank the media for helping tell our story.

APRIL

"<u>Outdoor Alert</u>" & MD News article: "Targeting Tick-Borne <u>Disease in Central</u> <u>New York</u>"

MAY

Dan Cummings' Newsmakers: "Lyme Disease" and Syracuse.com editorial: "Watch out for ticks, the bug you can do something about" JUNE

Syracuse.com video: "CNY scientists collect ticks to see if rare virus makes Lyme more dangerous" JULY Syracuse.com article: "Upstate, ESF aim to be national leaders in fighting Lyme, other tick-borne diseases"

OCTOBER

Syracuse.com article: "<u>Tick-borne</u> <u>bacteria that causes</u> symptoms worse <u>than Lyme disease</u> <u>found in CNY</u>"

We're 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!

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