

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 [Global Lyme Alliance](https://www.globallymealliance.org).

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,  
Board Chair



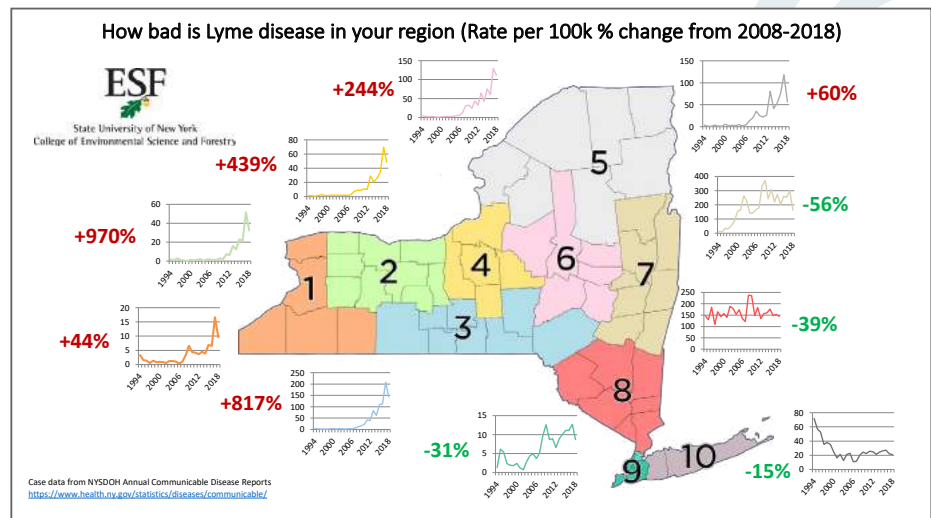
## OUR PURPOSE

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](http://cnylymealliance.org/lyme-stories)



## WE'VE EVOLVED FROM CONCEPT TO ORGANIZATION



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

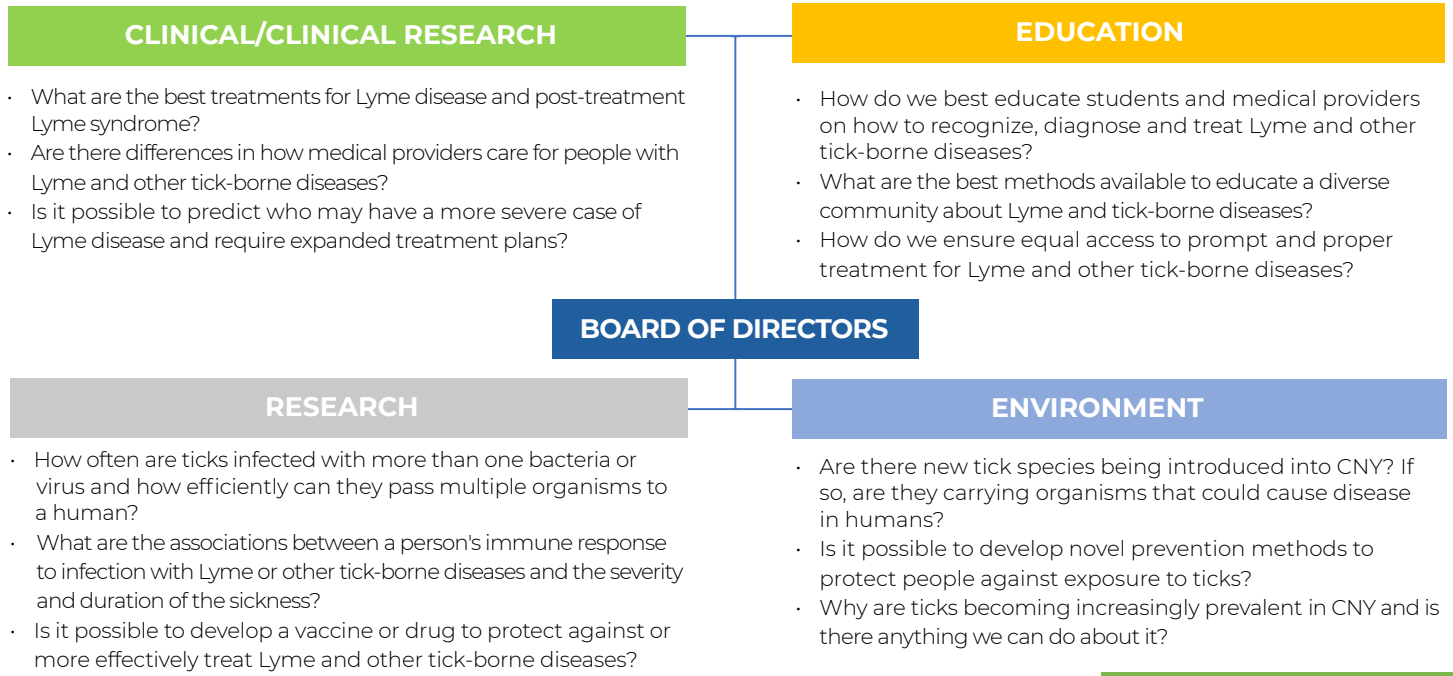
We're in the business of dissolving silos and connecting dots. "Collaboration" is the name of our game. *It's our differentiator.*

“ No one is doing it like this in the country. ”

- Scott Santarella, former CEO of the [Global Lyme Alliance](http://www.globallymealliance.org)



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



**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: <https://nyticks.org>.

**Received funds from seven foundations:**

•Allyn, CNYCF, Gifford, Mother Cabrini Health, Revoir, Reisman and Shineman

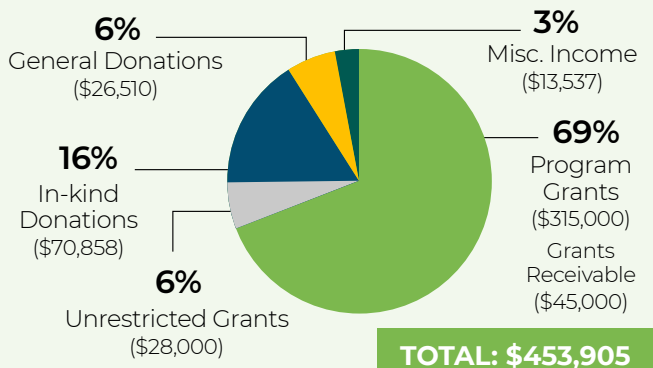


**Held education sessions** for a broad range of audiences, including community engagement professionals, garden clubs, Girl Scouts and its leaders, community organizations, Rotary clubs, Thursday Morning Roundtable and neighborhoods.

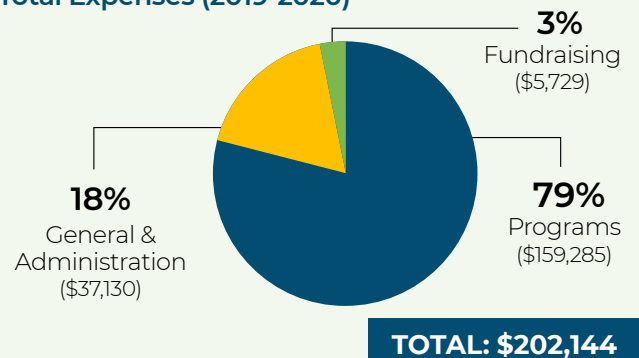
**Met with county health departments** and local and state elected officials.

**FINANCIALS TO DATE**

**Total Revenue and Support (2019-2020)**



**Total Expenses (2019-2020)**



## CONTRIBUTIONS TO DATE



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

### Gifts of \$1,000+

Elizabeth Eroll  
Zalie and Bob Linn  
Anne Messenger  
The Pinckney Family  
Kathy and Dan Ruscitto

### 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 \$100+

Catherine Bertini  
Kathryn Clarke  
Danielle Cummings  
Erin Duffy  
Shantina Hines Kyles

Cindy Leydet  
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Brandiss Pearson, EdD  
Heidi Puc, MD, FACP, ABIHM

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

### Gifts of Support

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Eric Canute  
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Christine Carter-Huffman  
Jarius Castro  
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Nina Langenmayr  
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Heather A. Waters  
Lesley Wendell  
Christine Werbeck  
Kasey West  
Martha Winterton

## LEADERSHIP TEAM



**Royale Scuderi**  
Executive Director



**Danielle Cummings**  
Chancellor,  
Chair, Communications  
Chancellor,  
Roman Catholic  
Diocese of Syracuse



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



**Shantina Hines Kyles**  
Registered Nurse



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



**Zalie Linn**  
Treasurer  
Chair, Finance



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



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



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



**Brandiss Pearson, EdD**  
Board Secretary  
Director, Community  
Engagement,  
St. Joseph's Health



**Heidi Puc, MD**  
FACP, ABIHM  
Founder and  
Physician-Owner,  
Integrative Medicine of  
Central New York, PC



**Kathryn Ruscitto**  
Co-Vice Chair



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



**Saravanan  
Thangamani, PhD**  
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



**Stephen J. Thomas, MD**  
Vice Chair  
Chief, Division of Infectious  
Diseases/Director,  
Institute for Global Health and  
Translational Science Infectious  
Disease Associates

## WHAT'S NEXT?

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

1.



**Broaden geographic scope**  
to a three-county area to  
include Onondaga, Oswego  
and Madison counties.

2.



**Design and run**  
a CME course and/or  
symposium.

3.



**Hire**  
an Education Coordinator.



## 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](http://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!**



<https://www.facebook.com/CNYLymeAlliance>



<https://www.instagram.com/cnylymealliance>



<https://twitter.com/cnylyme>



<https://www.linkedin.com/company/cny-lyme-and-tick-borne-disease-alliance>

## 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.

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

### A 2020 sampling:

#### APRIL

"[Outdoor Alert](#)" &  
MD News article:  
"[Targeting Tick-Borne  
Disease in Central  
New York](#)"

#### 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: "[Tick-borne  
bacteria that causes  
symptoms worse  
than Lyme disease  
found in CNY](#)"

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!**

