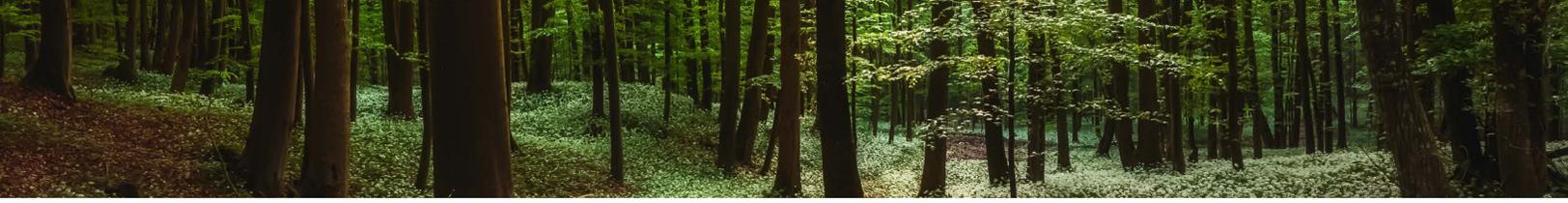


CENTRAL NEW YORK  
**LYME & TICK-BORNE**  
DISEASE ALLIANCE





## TENACITY

### We Heard You

We heard the parents who pulled their kids out of college because of Lyme disease.

We heard the 20-year-old who broke down describing his pain.

We heard one doctor say to the others in the room, “I thought I was going to die.”

We heard the elected official whose niece almost died of Lyme. And the one who raced his daughter to the emergency room, followed by her 5-night stay in the hospital.

We know what it's like to wake in the morning to deep exhaustion.

We know about the stabbing pain, the brain fog, the swelling joints, the extreme anxiety.

We heard about the years of tests and countless misdiagnoses.

We know what it's like to be dismissed, “It's just your imagination ... stress ... aging ... school ... work ... life ...”.

We know what it's like traveling thousands of miles to seek treatment.

We heard about the careers you lost because you couldn't perform.

We heard you when you went deep into debt because insurance didn't cover costs.

We heard you when you slid into depression.

We heard the anguish as you described your friend's death. Your mother's death.

We heard the countless “Lymies” in their underground conversations helping each other.

We heard you when you were desperate for help.

### The stories keep coming and we hear them. They're the “why” of the CNY Lyme & Tick-Borne Disease Alliance.

It only takes one person's anguished questions — Why can't I get better? Where can I go for help? — that motivates the Alliance to focus on our task of education. The reality is that we hear from far more than one, and we are tenacious in pursuing answers. Thank you.



Anne Messenger  
Board Chair



Royale Scuderi  
Executive Director



## OUR PURPOSE

The CNY Lyme & 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.

## WHAT WE DID IN 2022

- **Hired a full-time educator.**
- **Doubled the number of education sessions, tripling attendees to 3,000+**, from a broad range of audiences in Madison, Onondaga and Oswego counties.
- **Expanded our youth education programs to 1,000+**, twice the number of youths as the previous year.
- **Distributed 2,000+ tick kits**, up from 500 in 2021.
- **Hosted our first Legs Against Lyme Walk**, with 200+ registrants.
- **Hosted our first Lyme & Tick-Borne Disease Summit for 50 attendees**, with 30 providers receiving CME credit.
- **Substantially increased visibility and awareness** with TV and radio interviews, new PSA spots, expanding social media following, increasing website visitors and multiple billboards in more locations.
- **Continued building relationships with elected officials**, advocating for awareness and funding, resulting in \$68,000 in NYS funding awarded.



## TWO GROUNDBREAKING INAUGURAL EVENTS

### 2022 LYME & TICK-BORNE DISEASE SUMMIT

We were thrilled to have had a full house (medical doctors, scientists, physician assistants, nurse practitioners, vets, funders, patients and more) at the first-ever Lyme & Tick-Borne Disease Summit on October 20 and 21, 2022. So much listening, so many conversations, so much learning! All in a beautiful place tucked into the woods above an Adirondacks lake.

Thank you to our partners at Upstate Medical University Institute for Global Health and the Trudeau Institute!

[cnylymealliance.org/lymesummit](https://cnylymealliance.org/lymesummit)



## Feedback from summit attendees:



“Great conference! This should be an annual event! Information was both clinically relevant and comprehensible to non providers.”



“I think the voice of the people who have had Lyme disease talking about their experience was profoundly moving, and that's essential for doctors who may not have that much familiarity with Lyme disease, especially the chronic aspects, because it's a long journey they go through ... and they've had so many frustrations accessing medical care they were courageous in telling their story.” **Brian Fallon, MD, Director, Lyme and Tick-Borne Diseases Research Center, Columbia University**



“I'd like to say I listen 100% of the time, but none of us do. We do the best we can. Most doctors do, so I think it's good for a primary care doc to get perspectives from the whole range of people that this disease affects.” **Joe Augustine, MD, CNY Family Care**



“Lyme disease is really a worsening problem in Central New York and it's one that we need to have in the forefront of our brain so that we can practice prevention in terms of counseling our patients and, maybe most importantly, provide post-exposure prophylaxis in a timely manner or treat them when they present early signs of Lyme. The second aspect of this summit that was really impactful for me was learning about the burden and the struggles of post-treatment Lyme and how devastating that can be and the real need to be creative and empathetic and really partner with patients to try to get some solutions.” **Katie Anderson, MD, Upstate Medical University**

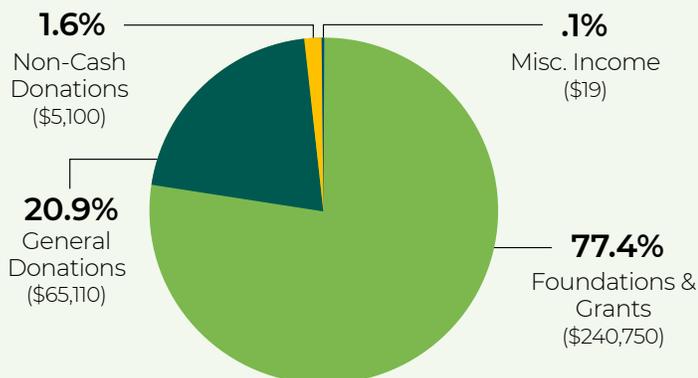
## INAUGURAL LEGS AGAINST LYME WALK

On May 21, 2022, we gathered Central New York's Lyme Warriors for the Inaugural Legs Against Lyme Walk at Onondaga Lake Park! With the leadership of Legs Against Lyme Walk Chair Nicole Sommovilla, our first-ever walk turned out to be an extraordinary, tick-free success. More than 200 participants, donors and sponsors supported our efforts, raising awareness and nearly \$15,000, which helps fund our innovative educational outreach and programming efforts. Save the date for our 2023 Legs Against Lyme Walk on May 13!



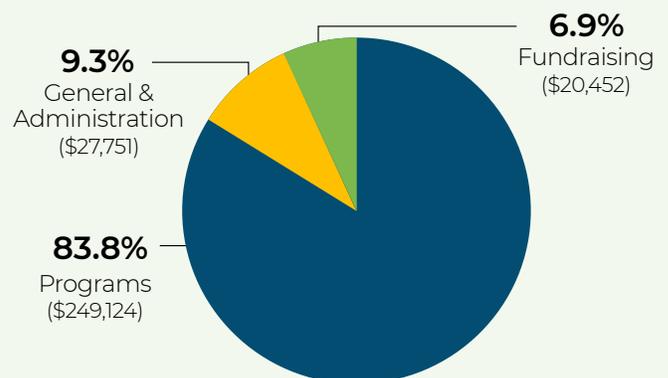
## 2022 FINANCIALS

### WHERE THE MONEY COMES FROM

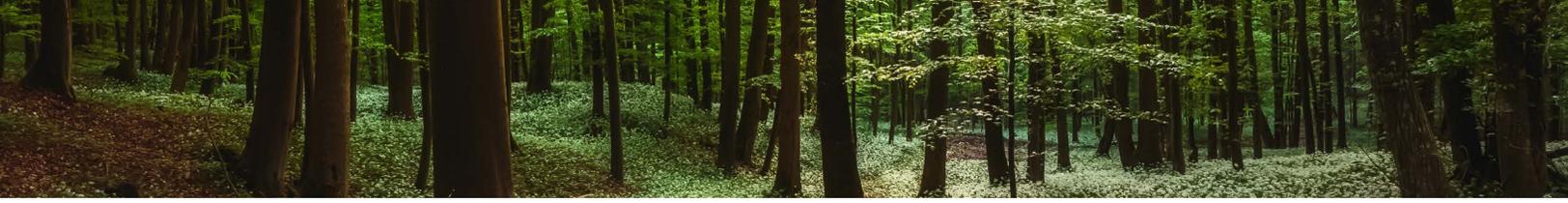


**TOTAL: \$310,979**

### WHERE THE MONEY GOES



**TOTAL: \$297,327**



## CONTRIBUTIONS IN 2022



### Foundation Support

- |   |                                  |
|---|----------------------------------|
| Dorothy and Marshall Reisman Foundation | Kinney Drugs Foundation          |
| Frank and Frances Revoir Foundation     | Mother Cabrini Health Foundation |
| Gorman Foundation                       | Richard S. Shineman Foundation   |

### Corporate Support

- |                               |                             |  |
|-------------------------------|-----------------------------|--|
| Ashley Winery                 | Metabolic Manlius, LLC      | SUNY Upstate Institute for Global Health |
| Excellus BlueCross BlueShield | Northern Mast Climbers, LLC | Warne/McKenna Advertising                |
| Hueber-Breuer Construction    | Pinckney Hugo Group         | Wegmans                                  |
| Insect Shield                 | Ranger Ready                |  |
| KeyBank                       | Salt City Coffee            |  |
| Kinney Drugs                  | The Steve Donigan Agency    |  |

### Gifts of \$1,000+

- |                |                            |                    |
|----------------|----------------------------|--------------------|
| Aminy Audi     | Eric Allyn & Meg O'Connell | Michela Hugo       |
| Anne Messenger | Kathy and Dan Ruscitto     | Zalie and Bob Linn |
| Christine Herb | Kristin Gamble             |                    |

### Gifts of \$500+

- Doug Wojcik
- Elizabeth Etoll
- The Pinckney Family
- William Magnarelli

### Gifts of \$100+

- |                   |                     |                  |                      |
|-------------------|---------------------|------------------|----------------------|
| Amy Allyn         | Dawn Penniman       | Linda Eldred     | Sarah A. Whitton     |
| Bonnie Whalley    | Deanna Allen        | Lisa Dunkle      | Saravanan Thangamani |
| Camille Hemlock   | Emilija Postolovska | Liza Shvartsman  | Shantina Hines Kyles |
| Chol Majok        | Erin Duffy          | Mary DeGroat     | Simone Seward        |
| Cindy Leydet      | Erin Foe            | Maureen Wopperer | Stephen J. Thomas    |
| Clare Morschauser | James Reed          | Molly Cummings   | Steven Hanks         |
| Colleen Pleasant  | Joseph Hardick      | Rita Reicher     | Sunny Aslam          |
| Cyndi Signorelli  | Julie Moore         | Roberta Goheen   | Theo Vermont         |
| Darlene Babcock   | Kline Jason Slottje | Royale Scuderi   |                      |
| David Rose        | Kristopher Paolino  | Ryan Dean        |                      |

## LEADERSHIP TEAM



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



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



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



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



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BCIDP, Chair,  
Governance Committee**  
Clinical Assistant Professor of  
Pharmacy Practice, SUNY  
Binghamton School of Pharmacy



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**Board Secretary**  
Spinal Cord Injury Manager



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Assistant Professor, SUNY  
College of Environmental  
Science and Forestry (ESF)



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Policy, MultiState Associates



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Chapter Chair, Women  
Presidents' Organization



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



**Christine Paul**  
Executive Director, Madison  
County Rural Health  
Council; Mental Health  
First Aid (MHFA) Instructor



**Georgina Pinckney**  
**Chair, Development  
Committee**  
Tick-Borne Disease Advocate



**Emilija Postolovska,  
MPH**  
Senior Analyst, Public  
Health, M.S. Hall & Associates



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



**Simone Seward, MPH, PhD**  
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Research and Programs  
Director, Center for Civic  
Engagement, SUNY  
Upstate Medical University



**Saravanan Thangamani, PhD**  
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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



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



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

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WSYR NewsChannel 9,  
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Allyn Foundation



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**Kathryn Ruscitto**  
Tick-Borne Disease  
Advocate



**Stephen Thomas**  
Director, SUNY Upstate  
Institute for Global Health  
and Translational Sciences



## WHAT'S NEXT?

We have a long to-do list for 2023. Four items at the top:

- 1. Increase community awareness and engagement** to address differing needs of diverse communities.
- 2. Expand our education program** to reach even more communities, especially those in rural isolation.
- 3. Host a second Lyme & Tick-Borne Disease Summit in 2023** with an enhanced curriculum and an expanded audience of healthcare professionals.
- 4. Partner with entities and organizations** currently serving our communities to 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 [cnlymealliance.org](http://cnlymealliance.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 tenacity, 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 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!**

