2024

ANNUAL
REPORT

LGDA

info@lgdalliance.org

lgdalliance.org

7901 4th Street N
STE 9153
St. Petersburg, FL 33702

ABOUT US

Patient voice is central to everything we do.

It’s the lifeline through all our work. As such, we engage patients whenever possible across our work for their input and perspective.

LETTER FROM LEADERSHIP

This year, we witnessed tremendous progress for the CLA community. From groundbreaking research to global awareness campaigns, our work continues to be guided by one principle: patients and families are at the center of everything we do.

Together, we expanded resources, advanced science, and amplified the voices of patients worldwide. With your support, we are not only building a stronger network—we are shaping a brighter future for those living with complex lymphatic anomalies.

Michael Kelly MD, PhD, Executive Director
Scot Wiesner, President, Board of Directors

OUR VISION

Patients with complex lymphatic anomalies have the support they need from peer, medical, and scientific communities to lead longer, higher-quality lives.

OUR MISSION

We connect patients and families to peers and networks of care, partner to advance new research, and educate the medical community to help all people navigating complex lymphatic anomalies have hope for a healthier tomorrow.

OUR PARTNERS

Uniting voices worldwide to accelerate research and improve lives.

LGDA partnered with LGD Alliance Europe and the Lymphatic Malformation Institute on the Alfie Milne Young Investigator Award and the Million Dollar Bike Ride. Together, through our joint advisory councils, we aligned research priorities with patient needs to advance progress for the global CLA community.

IMPACT AT A GLANCE

14,999
Visitors to our website

79
blog posts on research, mental health, and patient stories

5 Million
reached through patient stories in Rare Revolution Magazine

540
individuals connected to care via “Find a Physician” page

11
languages for the CLA Patient Guide, reaching 51 countries

$87,398
invested in research grants

5,000
number of video views on YouTube

19
countries contact us directly; 30 nationals represented in our patient registry

50+
hours of consultation with pharma and academic partners

INVESTING IN DISCOVERY AND INNOVATION

We awarded $87,398 in grants to advance science:

- C. Griffin McDaniel, 2024 Alfie Milne Young Investigator Award recipient, studied mutant-to-wild-type endothelial cell interactions in kaposiform lymphangiomatosis. His Research Network talk became our most-watched presentation, with 350+ views.
- Dr. Shoshana Greenberger (Sheba Medical Center & Tel Aviv University) investigated the role of ephrin B2 mutations in the pathogenesis Central Conducting Lymphatic Anomaly.

The CLA Research Network continues to expand, with 7 webinars in 2024 and 5,000 views of research videos on YouTube, connecting researchers, clinicians, and patients across borders.

Our Executive Director contributed 50+ hours of consultation to pharma and academic partners, ensuring projects quality of life and therapies reflect patient needs.

Welcomed Dr. Willemijn Klein from Radboudumc Amalia Children's Hospital in Nijmegen, Netherlands to the Medical and Scientific Advisory Council.

KNOWLEDGE WITHOUT BOARDERS

- The International CLA Patient Registry now has 564 enrolled patients from 30 countries, strengthening global research and collaboration.
- Individuals from 20 countries reached out directly to LGDA with questions and requests for support.
- The CLA Patient Guide expanded to 11 languages, including Arabic, reaching families in 51 countries.
- More than 500 families visited our “Find a Physician” page to connect with specialists.
- Patients shared stories on our website and at conferences, bridging lived experience and medical expertise.

VOICES OF PATIENTS AND FAMILIES

Every story told strengthens our community. In 2024, those voices touched millions around the world.

- Patient and family stories reached more than 5 million people worldwide through blogs, social media, and conferences. These narratives educate professionals, inspire families, and strengthen our community.

- At the ISSVA Congress, in Madrid, Spain, we shared resources and strengthened collaborations.

- We supported clinical trials including:
  - Relay Therapeutics: RLY-2608 (mutant-selective PI3K inhibitor).
  - Palvella Therapeutics: QTORIN 3.9% rapamycin gel for microcystic lymphatic malformations.
  - Ohio University: survey with female patients and their experiences related to pregnancy, fertility, and family planning.

STRENGTHENING CAPACITY FOR TOMORROW

- **Registry Expansion:** A new platform and surveys will capture patient experiences, quality-of-life, and caregiver insights–while also expanding to include isolated lymphatic malformations, ensuring research reflects the full spectrum of the community.

- **Volunteer Growth:** Partnership with Emory University School of Public Health gave students rare disease project experience, while expanding our impact.

- **Youth Engagement:** Our annual T-shirt contest gave young warriors a creative way to raise awareness.

- **Rebrand:** We will launch a rebranding initiative to expand our identity beyond CLAs to include isolated lymphatic malformations, ensuring our organization represents the full community and aligns with updated ISSVA classifications.

STATEMENT OF FINANCIAL POSITION

FISCAL YEAR: JULY 1, 2024 TO JUNE 30, 2025

ASSETS

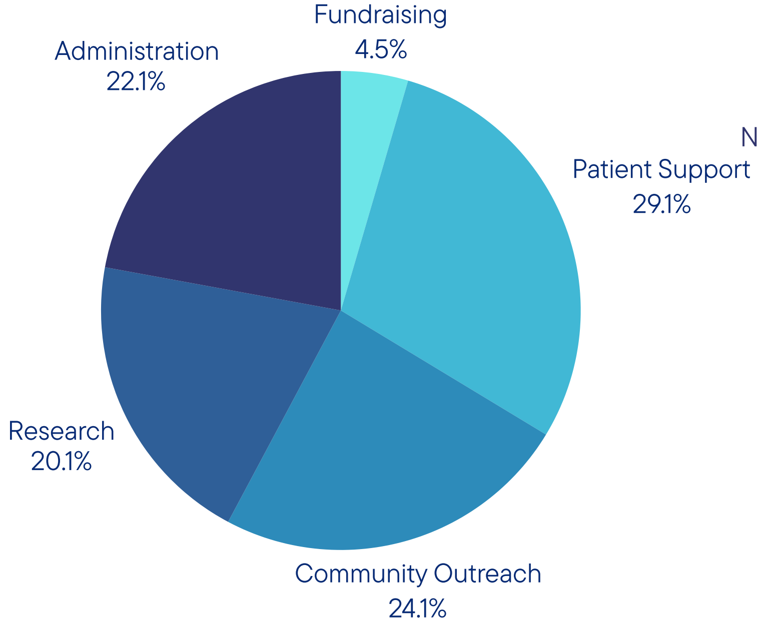
LGDA Operating Accounts	$228,280
Charles Schwab Investments	$125,545
Total Current Assets	$353,825

INCOME/EXPENSES

Income	$113,613
Expenses	($152,600)
Investment Income	$4,777
Total Net Income	($34,210)

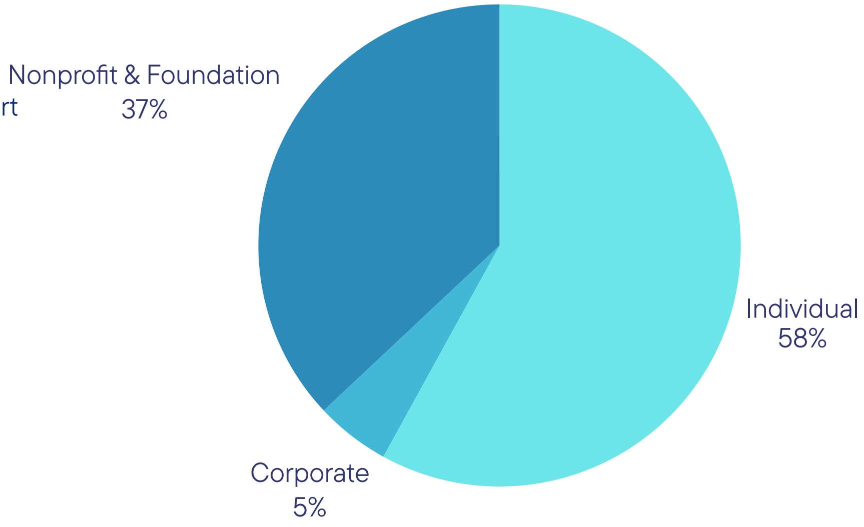
Expenses Breakdown

2024-2025



Income Breakdown

2024-2025



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