ANNUAL REPORT 2023

LGDA

WHO WE ARE

BOARD OF DIRECTORS

- Scot Wiesner, Chair
- Scott Goldfarb, Member and Treasurer
- Tiffany Ferry, Member
- Mitch Maersch, Member
- Sean Chastain, Member
- Kevin Martin, Member

STAFF

- Michael Kelly, MD, PhD, Executive Director
- Louise Murgia, Director of Operations
- Tracy Milne, Support Services

VISION

Patients with Complex Lymphatic Anomalies have the support they need from peer, medical and scientific communities to lead longer, higher-quality lives.

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.

PARTNERS

Throughout the year, LGDA collaborated with LGD Alliance Europe and the Lymphatic Malformation Institute on research initiatives such as the Young Investigator Awards and the Million Dollar Bike Ride. We also worked with both groups for our International Conference on CLAs. Our joint Medical and Scientific Advisory Council (MSAC) and Patient and Community Advisory Council (PCAC) also include members from one or both partner organizations.

IMPACT

7

LGDA receives an average of 7 inquiries per month for support, resources, and locating physicians

24

Number of countries contacting LGDA with inquires. Increase of 33%

59

Number of countries represented in the International CLA Patient Registry

270

Number of times our Patient Guidebook for CLAs was downloaded from 9 lanagues

362

Number of visits to our Guide for Primary Care Physicians

560

Number of patients in registry
An increase of 7%

International Society for the Study of Vascular Anomalies (ISSVA)

- Exhibitor at the World Congress in Spain
- Translated the CLA Guide for Primary Care Physicians into Spanish and distributed

CLA AWARENESS

14,171

Website Visitors
42% Increase

30,412

Webpages Viewed
38% Increase

3,654

Social Media Followers
3% Increase

HIGHLIGHTS

- Joined Rare Revolution Magazine, as a partner, to share stories about CLA patients
- Translated the Patient Guidebook to Japanese - our 10th translation! Thank you to our volunteers
- CLA Awareness Day: created social media templates for the CLA Community to use. Reached an additional 25,000 through “takeover Tuesday” on Rare Revolution Magazine‘s social media

SCIENCE & RESEARCH

2023 MDBR GRANT

The 2023 MDBR grant was awarded to Bryan Sisk at Washington University. Funding was used to create the CLA Chatbot, a tool retraining ChatGPT to provide reliable answers about CLAs. This aims to improve patient-caregiver communication, enhance access to accurate information, and support future research, with potential application to other rare diseases.

$60,689

Money raised in 2023 for MDBR

2024 MDBR TOTAL

A total of $62,398 was raised this year! We extend our heartfelt thanks to every donor, participant, and supporter, both near and far, whose dedication and generosity made this possible.

$62,398

Money raised in 2024 for MDBR

Speakers at International Scientic Conference	Total views of International Scientific Conference videos	Total Funds raised for CLA research via MDBR
28	**2,054**	**$1 M**

ALFIE MILNE YOUNG INVESTIGATOR AWARD

The 2023 recipient was Nour C. Bacha, PhD, from the Columbia University Medical Center in New York. The $25,000 grant is for the project “Assessment of Lymosomal Dysfunction in Lymphatic Anomaly Pathogenesis”.

STATEMENT OF FINANCIAL POSITION

FISCAL YEAR: JULY 1, 2023 TO JUNE 30, 2024

ASSETS

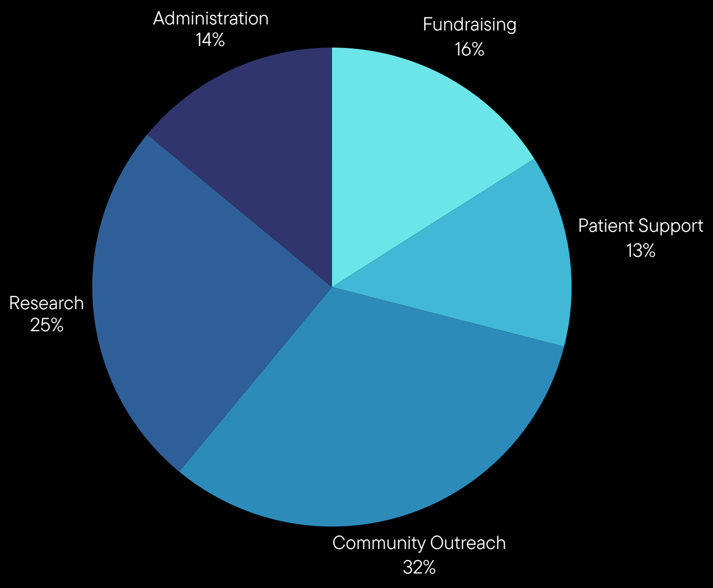
LGDA Operating Accounts	$268,109
Charles Schwab Investments	$114,810
Prepaid Expenses	$634
Total Current Assets	$383,553

INCOME/EXPENSES

Income	$262,687
Expenses	($310,195)
Other Income	$5,155
Total Net Income	($42,354)

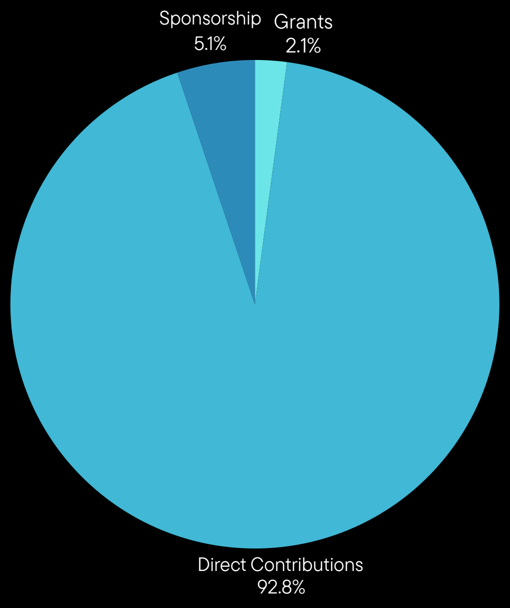
Expenses Breakdown

2023-2024



Income Breakdown

2023-2024



IMPACT

563

Average number of reactions on social media posts per quarter

2

Mental Health Webinars with over 120+ views.

77

Blog post summaries about advocacy, mental heath, stories, and daily living with CLAs

270

Number of times our Patient Guidebook for CLAs was downloaded from 9 lanagues

“Thank you so much for sending me all this information, really appreciated”

A young adult from the UK, struggling to find a diagnosis for unusual symptoms, received invaluable support. We provided her with educational resources on GSD, information to share with her primary care doctor, and details about a UK specialist who could help with the diagnosis.

“Thank you for the help. Happy to be part of this network."

When a Brazilian family with a child diagnosed with CCLA reached out to the LGDA, we connected them with five families who share the same diagnosis. This fostered a supportive network and deepened their understanding.

WE COULDN'T HAVE DONE IT WITHOUT YOUR GENEROUS SUPPORT

We extend our heartfelt gratitude to our generous donors for their unwavering support, which empowers us to make a meaningful difference in the lives of CLA patients and their families.

Laura Albers
Joel Anderson
Eva Monastersky
Jen Arauz
Maxine Armstead
Josué Barba
Cheryl Bartholomew
Jami Barzelatto
Myrna Barzelatto
June Bates
Tim Bazyn
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