ANNUAL REPORT 2022

LGDA

Who We Are

BOARD OF DIRECTORS

Scot Wiesner, Chair
Scott Goldfarb, Member
Tiffany Ferry, Member
Mitch Maersch, Member

STAFF

Michael Kelly, MD, PhD, Executive Director
Louise Murgia, Director of Operations
Laura O'Neal, Director of Fundraising (til 8/1/2023)
Ashley Capps, Director of Fundraising
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.

In 2020, LGDA was selected for the Chan Zuckerberg Initiative's Rare As One Project — a group of 30 patient-led organizations that are accelerating research and driving progress in the fight against rare diseases.

Through Rare As One, the LGDA expanded and will continue to develop a community which includes three interconnected networks: patient, clinical, and scientific to assist those affected by CLAs.

Rare
As
One

Throughout the year, LGDA worked in partnership with LGDA Europe and the Lymphatic Malformation Institute on research initiates such as the Young Investigator Awards and Million Dollar Bike Ride. We also completed the Patient Guide and translations. We worked with both groups for our International Conference on CLAs.

Our joint Medical and Scientific Advisory (MSAC) and Patient and Community Advisory (PCAC) councils also has a member from one or both partners.

LMI Lymphatic Malformation Institute

LGD Alliance Europe
for Complex Lymphatic Anomalies

OUR IMPACT

8, 154 VISITORS
Website visitors

3, 482 FOLLOWERS
15% increase in social media followers

18,864 WEBPAGES
# of webpages viewed by visitors

1,352 READERS
people on newsletter list

9 LANGUAGES

Patient guide is available in English, French, Chinese, Spanish (Europe and Latin America), German, Italian, Portuguese (Europe and Brazil)

Translations are made possible from the Robert & Toni Bader Charitable Foundation

Sharing Research

- 131 Research Network members
- 7 scientific webinars; average of 30 attendees
- New #sciencedsaturday on social media
- New lay research summaries
- The MSAC defined CLA research priorities and the framework for the scientific conference.

Funding Research

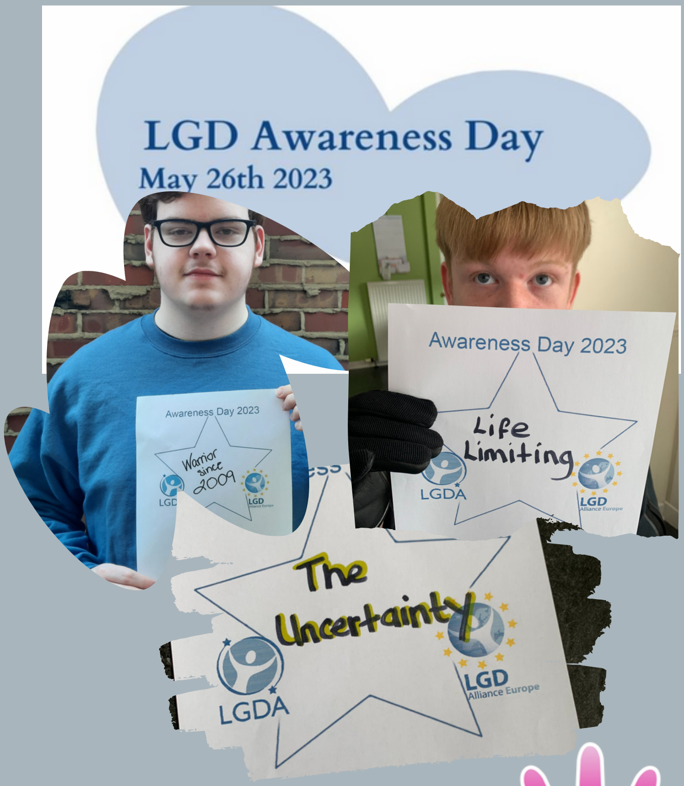
- $60,679 raised for 2023 MDBR
- $50,000 raised for two Young Investigator Awards
- $25,000 donated for the Alfie Milne Young Investigator Award

Patient Registry

- 521 registered patients
  - 60% North America
  - 32% Europe
  - 8.0% Other
- 11% increase from 2021

Patient Support

- 2 mental health webinars thanks to a grant from Global Genes
- 70 emails from the public about CLAs
- Quarterly newsletter to the CLA Community
- 38 new members in our two online support groups
- An 52% increase of new member from 2021
- The PCAC reviewed and provided feedback on our new lay summaries



OUR ACTION

RARE DISEASE DAY®

Million Dollar Bike Ride	• Raised $60,657 in 2023 • Raised, over the past 10 years, more than $970,000 for MDBR grants. This includes matching funds from University of Pennsylvania
LGD Awareness Day	• Our biggest social media outreach campaign • “Take over” on Rare Revolution Magazine’s social media with over 25,000 followers to promote CLAs
Rare Disease Day	• Special themed newsletter • Social media campaign with participation from round the world

STATMENT OF FINANCIAL POSITION

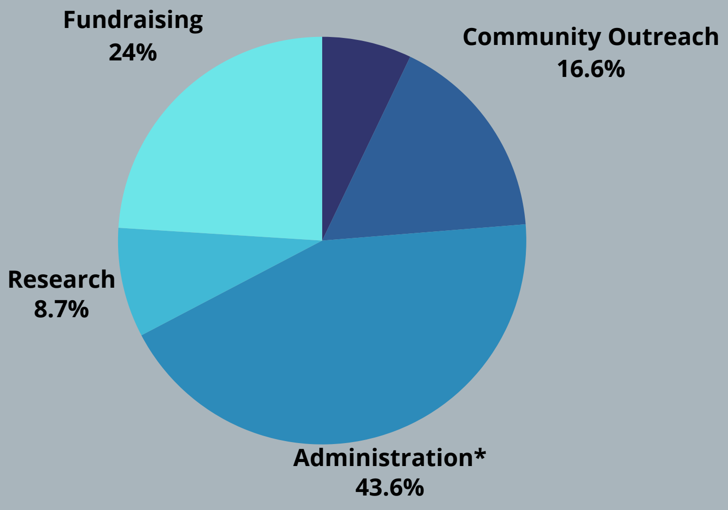
Fiscal Year : July 1, 2022 to June 30, 2023

Assets

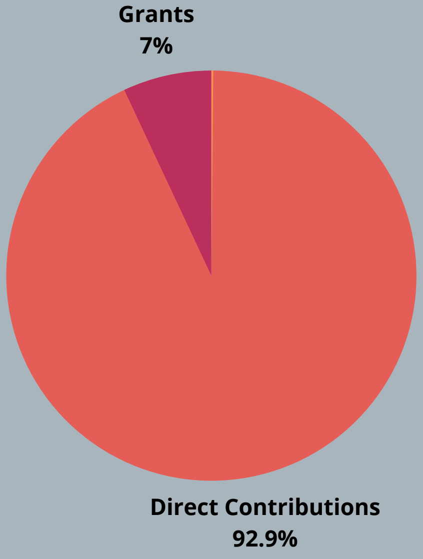
LGDA Operating Accounts	$305,672
Charles Schwab Investments	$109,655
Prepaid Expenses	$6,539
Total Current Assets	$421,866

Income/Expenses

Income	$118,513
Expenses	($280,894)
Other Income	$2,428
Total Net Income	($159,952)



Expenses Breakdown
2022-2023



Income Breakdown
2022-2023

*Program hours were placed under administration in this fiscal year. For the next fiscal year, expenses will be categorized to the proper programs.

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.

Amanda Fawcett
Amanda Haldeman
Andrea Genette
Anna Lawton Creger
Anna Maffitt
Anne Euchler
Barbara Ertl
Barbara Watts Asmus
Beulah Brown
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Stacey Flores
Stephanie Hornby
Suzanne Fitzsimmons
The Lymphatic Malformation Institute
The Marksmen Company
Thread Strategies
Tiffany Ferry
Tim Hudson
Timothy Hester
Tracy Milne

Donations from:
July 1, 2022 - June 30, 2023

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