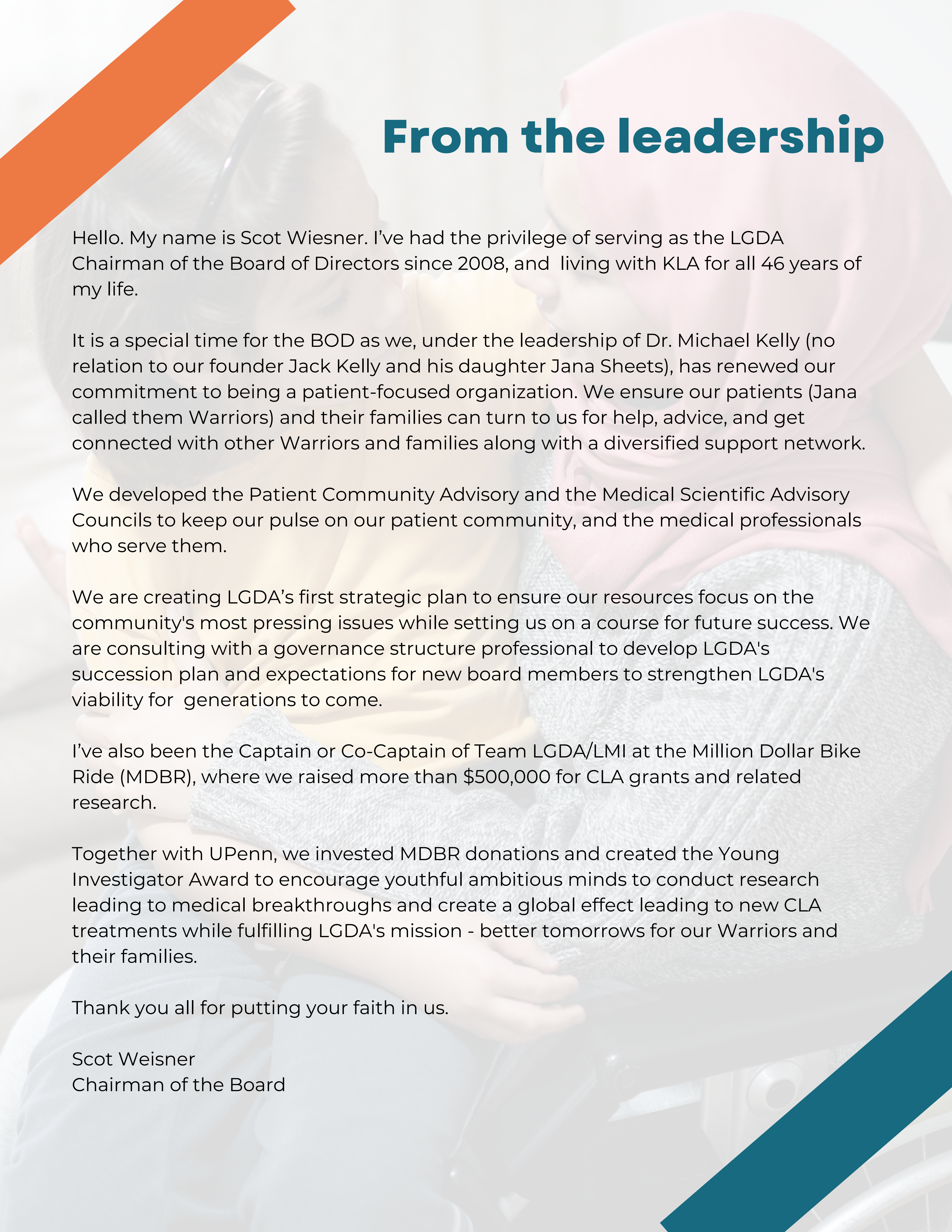
2021

Annual REPORT

LGDA

✉ info@lgdalliance.org

🌐 www.lgdalliance.org



From the leadership

Hello. My name is Scot Wiesner. I've had the privilege of serving as the LGDA Chairman of the Board of Directors since 2008, and living with KLA for all 46 years of my life.

It is a special time for the BOD as we, under the leadership of Dr. Michael Kelly (no relation to our founder Jack Kelly and his daughter Jana Sheets), has renewed our commitment to being a patient-focused organization. We ensure our patients (Jana called them Warriors) and their families can turn to us for help, advice, and get connected with other Warriors and families along with a diversified support network.

We developed the Patient Community Advisory and the Medical Scientific Advisory Councils to keep our pulse on our patient community, and the medical professionals who serve them.

We are creating LGDA's first strategic plan to ensure our resources focus on the community's most pressing issues while setting us on a course for future success. We are consulting with a governance structure professional to develop LGDA's succession plan and expectations for new board members to strengthen LGDA's viability for generations to come.

I've also been the Captain or Co-Captain of Team LGDA/LMI at the Million Dollar Bike Ride (MDBR), where we raised more than $500,000 for CLA grants and related research.

Together with UPenn, we invested MDBR donations and created the Young Investigator Award to encourage youthful ambitious minds to conduct research leading to medical breakthroughs and create a global effect leading to new CLA treatments while fulfilling LGDA's mission - better tomorrows for our Warriors and their families.

Thank you all for putting your faith in us.

Scot Weisner
Chairman of the Board

From the leadership

Hello, I'm Mike, and I'm honored and humbled to serve as leader of the LGDA. I have been a part of the CLA community for over 20 years as a doctor, scientist, advocate, and now the Executive Director of the LGDA.

The past year has been transformative for both our organization and the CLA community. At LGDA the torch was passed from long-time president, Jack Kelly to me.

As our new leader my philosophy is to build on the solid organizational foundation that Jack and his colleagues have established, which includes embarking on new initiatives and advancing our ongoing efforts. This annual report is a new initiatives to communicate our successes to the CLA community. We look forward to sharing our efforts in future annual reports.

We have leveraged the Rare As One award from the Chan Zuckerberg Initiative to bring in new faces with new ideas and a renewed energy, expanded our patient support capabilities and research network, and upgraded the CLA global registry. We have partnered with the Lymphatic Malformation Institute (LMI) and LGDA Europe to align priorities and resources to best impact the CLA global community.

Finally, we are embarking on a strategic planning process inclusive of our patient, medical and scientific communities that will help plot the future for the LGDA and determine how we can best meet the needs of our patients and their families.

It is truly a transformative time. But critical work remains. Throughout the following pages, we welcome you to learn more about all the pivotal happenings that have the potential to transform and improve how we support, treat, and – one day – cure CLAs. Together, with you, our incredibly supportive and generous community, we can create meaningful progress.

Fight ON!

Mike Kelly
Executive Director, LGDA

Board of Directors

Scot Weisner
Chair

Mitch Maesch
Director

Scott Goldfarb
Director

Tiffany Ferry
Director

Michael Kelly, MD, PhD
Executive Director

Who is LGDA?

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.

History

Jana first experienced symptoms at 6 years of age and was diagnosed with lymphangiomatosis in the 5th grade. She easily broke bones throughout her life and was restricted from physical activity. Due to the disease, she had a lung transplant in her late 20s. In the years that followed, she dedicated her time to building a community supporting patients and their families. Jana died at the age of 35 in 2010.

Her vision continues to grow and expand as patients are connected with peers, clinicians, and researchers with the goal of patient driven research, treatment, and support.

Twenty years of never knowing another person with my disease inspired me to help others.

Jana Sheets, LGDA Founder

POINTS OF PRIDE

LGDA

Patient Registry

The International LGDA Registry for Lymphatic Malformations is a place where medical information, family history, and other related information is stored for patients with CLAs. This vital information is used for medical research and clinical trials to better understand these anomalies and to develop new treatments.

2021 Total Registrations:
464

34 New Registrations
7% Increase

New Registrations are from:

US/Canada - 56%
Europe - 29%
Other - 15%

New Registrations Found the Registry through:

LGDA Website - 23%
Facebook - 17%
Google - 17%
Physicians - 17%

LGDA Investments

We recognize that the research and scientific communities are vital to our patient support programs and develop activities that are tailored a patients’ wellbeing.

CZI Seminar Series


Bone Remodeling Alterations in Gorham-Stout Disease

Michela Rossi, PhD
Bone Physiopathology Research Unit
Bambino Gesù Children’s Hospital
Rome, Italy

The seminar series is a peer-to-peer program allowing researchers to learn from each other and provide feedback on current studies. The questions and comments that emerge can create new research ideas or strengthen current projects. Seven webinars were held in 2022, and eight were held in 2021.

This is a collaborative effort between LGDA and LMI. The 2022 webinars are available on the LGDA YouTube page.

International Conference on Complex Lymphatic Anomalies

In October 2021, LGDA, in cooperation with LMI, hosted the International Conference on Complex Lymphatic Anomalies with 27 speakers and over 200 attendees, from around the world, with topics on genetic causes of CLAs, treatments for CLAs, and new technology for research. Members of our patient community shared their personal stories and experiences through out the conference.


TREATMENT OF CCLA

Kristen Snyder, MD
Children’s Hospital of Philadelphia
Pennsylvania, USA

Saturday October 2, 2021
10 AM EST

REGISTER NOW
https://cvent.me/gMxMa9

Videos are available on the LGDA YouTube page.

LGDA Investments

We recognize that the research and scientific communities are vital to our patient support programs and activities which are tailored for a patients' wellbeing.

Meet the Medical and Scientific Advisory Council

They will provide a singular advisory voice to to shape global care and research for the CLA community.

Members:

- Chair: Matt Hawkins, MD
  Children's Hospital and Medical Center (Georgia)
- Juan Carlos Lopez-Gutierrez, MD, PhD
  Hospital Universitario La Paz (Spain)
- Miikka Vikkula, MD, PhD
  Institute de Duve (Brussels)
- Tim LeCras, PhD
  Cincinnati Children's Hospital (Ohio)
- Dong Li, PhD
  Children's Hospital of Philadelphia (Pennsylvania)

Future CLA Researchers

Young Investigators Award

The award cultivates the best and brightest future professionals who are committed to CLA research. LGDA, in cooperation with partners and the Orphan Disease Center, funded two awards of $25,000 to early career researchers, such as postdoctoral and clinical fellows or instructors, pursuing promising research ideas related to CLAs. The 2022 awards were made possible from donations raised for the 2021 Million Dollar Bike Ride.

Recipients
Michela Rossi, PhD
Location: Bone Physiopathology Research Unite, Bambino Gesu Children's Hospital, Rome
Mentor: Andre Del Fattore
Title: *Analysis of a new therapeutic approach to inhibit osteolysis in Gorham-Stout Disease*

Silvia Martin Almedina, Senior Postdoctoral Fellow
Location: St. George's University of London
Mentor: Pia Ostergaard
Title: *Molecular mechanisms of EPHB4 pathogenesis – towards new treatment development for lymphatic anomalies*

Our Community Outreach

Breaking Community News

LDGA is increasing it's outreach to the CLA community and continues to educate the public about CLAs. Our newsletter was relaunched and increased our social media reach.

72 individuals
Ask about CLAs
2021

Located in:
US/Canada - 85%
Internationally - 15%

Contact us by:
Website - 72%
Email - 28%

18 Joined
Facebook
Support Group
2021

2,970
Social Media
Followers
September 1, 2022

33 Sessions
Virtual Support Groups
2021

The Patient Voice

Extraordinary Measures:
The Patient as a
Research Partner

"My wish is to help further develop a hopeful and caring community with my fellow patients. No one should ever feel alone as they are undergoing their medical journey."

Meet Liz Bovee who is a patient advocate within the LGDA community and a member of the Patient Community Advisory Council (PCAC).

As an adult with GLA, she is passionate about building and leveraging a community to empower fellow patients and to help them develop their own voice to aid in research and treatment advancements for patients living with CLAs.

Listen to her story.

Her interests include searching for the best cup of coffee, enjoying long walks with her Goldendoodle Butterscotch, and travel.

Our Community Outreach

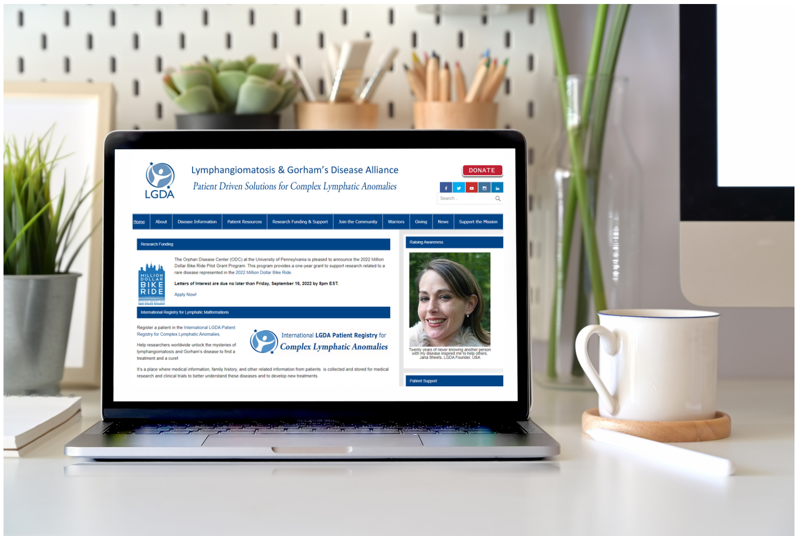
Relaunched Newsletter

The newsletter comes with a new name and focus. In partnership with LGDA Europe and LMI, the *Community Voice* was launched in August of 2022. We aim to keep the global CLA community abreast of important events, exciting research findings and new opportunities and updates. Help us keep the *Community Voice* relevant and meaningful by providing updates, content, and your feedback.

Say Goodbye to our Website...

And say "hello" to a new look.

LGDA will be launching a new website this fall focused on new resources, updated medical information, and welcome for the entire CLA global community.



Donor Spotlight

A Visionary Leader with a Heart of Gold

Meet Tracy Milne. With her unassuming charm and authenticity, Tracy is much beloved in both our US- and European-based patient family communities. She is usually their first point of contact as they navigate the often daunting path to and after CLA diagnosis since she manages LGDA's patient Facebook support groups. However, her impact and role in the lives of the global community of CLA patient families has been far greater than most realize.

Born in Leiston, England, as a teenager Tracy would leave friends and family to move away to Aberdeen, Scotland, her current home, with her partner, Mark. She admitted that she was "very, very young" and that theirs "was a love affair." Some years later, they married and went on to have two boys. Their second child, Alfie, at the age of 1 year old developed unexplained swelling in one leg and shortly thereafter was diagnosed with a CLA.

She felt lost and needed to get back some control, which is why she first became involved in LGDA 10 years ago. She describes her attendance at LGDA's in-person conference back in 2014 as "a magical memory." A few years prior, she'd started her own foundation in Alfie's honor which was buoyed financially by family and friends. Tracy recalls, "We were told he probably wouldn't reach his fifth birthday...but he did. He did reach his fifth birthday. After that, you know, it has been a blessing. We just have to keep focusing on the here and now," chuckling, she added, "And now, he's 15 with a teenager attitude."

Tracy helped raise £325,000 in support for CLA-specific research throughout her tenure as her foundation's director. Since its dissolution, she has remained an incredibly engaged member of our community through her membership on LGDA Europe's board of directors and as Programs Assistant for LGDA. One would think that a woman of such tenacious vision might have little time for much else, but Tracy enjoys singing alto as part of the UK's award-winning Rock Choir. A local contemporary chorale group with chapters throughout that country, the Rock Choir has released albums and is often a fixture on the UK social scene.


Tracy Milne
LGDA Donor

From all of us here at LGDA, brava Tracy!

Patient Support

Renewing our Commitment to Patients

Meet the Patient Community and Advisory Council (PCAC) . It's dedicated to supporting a global community of of CLA patients, medical professionals, and researchers through shared information, networking, and funding.

It's mission is to provide a singular advisory voice to assist in our planning and utilization of resources to maximize impact on the CLA rare disease community.

The PCAC will work with MSAC to ensure coordination of projects and ensure accuracy of medical information. PCAC held it's first meeting in September 2022.

Members:
- Chair: Diane Bomberg, parent (Nebraska)
- Sarah White, patient (United Kingdom)
- Liz Bovee, patient (Pennsylvania)
- Jennifer Boyce, parent (Canada)
- Tony Aguillon, parent (Michigan)

The Patient Voice

The Gene:
One Patient's Journey
from Diagnosis to a
Targeted Treatment

Meet Taylor Lewis, a CLA patient with generalize lymphatic anomaly (GLA) and a volunteer for LGDA support groups. She is a mental health therapist by day and a proud goldendoodle mom to Chewie and wife to her caring and supportive husband Alex.

Listen to her story.

Taylor has learned two great lessons through living with a chronic disease:

- The importance of advocacy and believing that coming together will provide hope and change for the future.
- When one opportunity is taken away in life, another will present itself and you may find it to be even more fulfilling.

Million Dollar Bike Ride

Million Dollar Bike Ride

LGDA, LMI and LGDA Europe participated in the University of Pennsylvania, Orphan Disease Center's Million Dollar Bike Ride. Through your generous support, we have raised over $800,000 in the past eight years support CLA research.

Many of the researchers who presented at the 2022 International Society for the Study of Vascular Anomalies were past recipients of this award.

In 2022, your support generated over $75,000 to continued research to fight CLAs.

See a list of recipients.

We Honor Our Top MDBR Fundraisers and Fundraising Families

The Sutherland and Seed Families (US)
The Jay Williams Family (US)
The Kilgour Family (UK)
The Ferry Family (US)
Tracy Milne (UK)
Scot Wiesner (US)
John Fay (US)

Why it matters?

Meet Dr. Max Itkin.

He, along with Dr. Yoav Dori, was LGDA's first MBDR grant recipients in 2015. Funds raised through the CLA global community helped them create an imaging system that established a standard of care for our patient community.

Your donations to the MDBR changed patients' lives.

Learn more.

We Honor Our Top MDBR Individual Donors!

John Dionne
Lawrence "Larry" Seed
Linda Sutherland
Margaret Seed
Mike Kelly
Susan Mudd
Rita Ferry
Tiffany Ferry

Million Dollar Bike Ride

Thanks to Our Donors

Andrea D. Genette
Andrew Jones
Andrew Stallings
Arthur Rhatigan, Jr.
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Biz Fay
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Sherry Powell
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Stephanie S. Summers
Sue Gardiner
Susan Mudd
Susan Pruitt
Suzanne Fitzsimmons
Yvette Steiger
and MANY anonymous donors!

Statement of Financial Position

Fiscal Year : July 1, 2021 to June 30, 2022

Assets

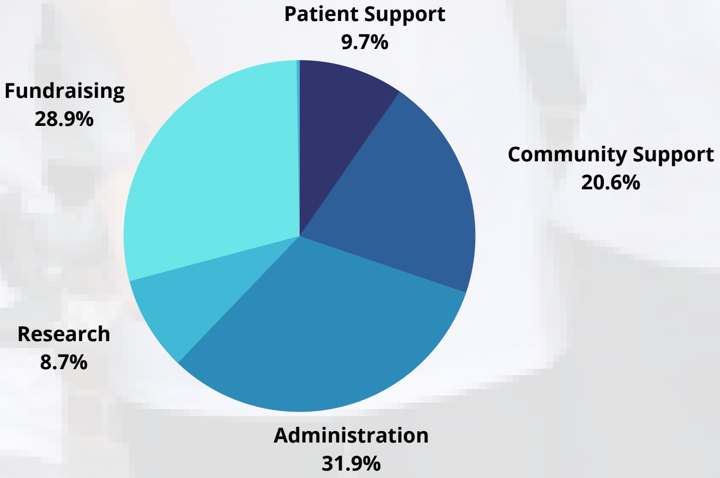
LGDA Operating Accounts	$245,312
CZI Grant Accounts	$226,583
Charles Schwab Investments	$107,246
Total Current Assets	$579,142

Income/Expenses

Liabilities	$272
Income	$320,875
Expenses	$319,777
Net Operating Income	$1,098
Net Other Income	($5,629)
Net Income	($4,531)

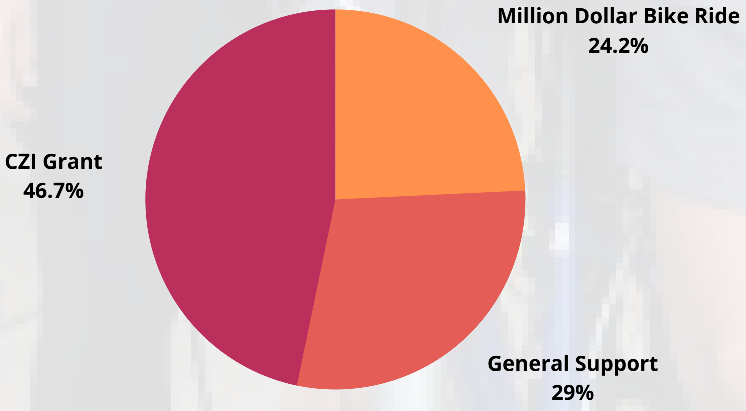
Expenses Breakdown

2021-2022



Income Breakdown

2021-2022



Fundraising & Development

In FY 2022, the LGDA community donated $170,875 to support projects and programs. LGDA also received $150,000 from a CZI grant.

Million Dollar Bike Ride	General Support	CZI Grant
$ 77,809	$ 93,066	$ 150,000

CZI Grant

Rare
As
One

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

The Project aims to strengthen the efforts of the selected patient-led groups and will help these communities of patients, researchers, and clinicians work together to advance progress against their diseases and scale these efforts.

CZI provided funding of $600,000 over three years to build organizational capacity and sustainability and to lower the barriers to patient-led research and enable patient communities to learn from one another.

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.

Our Donor Recognition

Thank you to all our donors between 2021 and Aug 2022.
Nothing would be possible without your support.

- Anonymous
- Adayna Gonzalez
- Alan McDaniel
- Allison Rucker
- Andrea Allred
- Andrea Genette
- Andrew Jones
- Andrew Stallings
- Anita Jeyakumar
- Anita Martinson
- Anne Drews
- Arthur Rhatigan Jr.
- Ashley French
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- Donald Wiener
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- Egil Hertland
- Elizabeth Welch
- Emma Skingle
- Emmanuel Boardman
- Eric Gonzalez
- Eva Monastersky
- Fidelity Charitable
- Frank Biello
- Friends of Million Dollar Bike Ride
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- Gary Mudd
- Gemma Berry
- Gillian Ellis-Rendall
- Grace Ferry
- Gregg Foster
- Gregory Tencza
- Guy Doyal
- Guy Oster
- Hannah Brailsford
- Hannah Ferry
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- Heather x
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- Howard Lyle
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- Jack Kelly
- Jace Canty
- Jade Tenreiro
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- James Williams Jr
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- Jay Williams
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- Jeannette Cormier
- Jeffrey Domke
- Jennifer Ballwahn
- Jennifer Gilbert
- Jennifer McBride
- Jessie Zames
- Jim Roy
- Jina Wolf
- Joan McCormick
- Joanne Tischer
- Joe Belisari
- John DIonne
- John Fay
- John Manser
- John McDonald
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- Jonathan McKenzie
- Jordan Widdowson
- Joseph Lexa
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- Kathleen Wilson
- Kathryn Marcket
- Kelly Brown
- Kenneth Hicks
- Kevin Conn
- Kevin Martin
- Kim Miller
- Kingfisher Foundation
- Donor Advised Fund
- Larry Seed
- Laura Albers

Our Donor Recognition

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Leilani Barna
Leslie Morris
LGDA Europe
LGDA Belgium
LGDA UK
Libby Rieke
Lisa Klepper
Lisa Rinaldi
Livia Quan
Louise Murgia
Lucy Ferry
Luda Kotlyar
Lynette Jenkins
Mandi McGee
Mandy Kilgour
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Timothy Hester
Timothy Kelly
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Yvette Steiger

To all those that created online fundraisers, donated to them, and shopped on AmazonSmile to support LGDA.

Donate!

LGDAlliance.org

DONATE

Start a Facebook Fundraiser

Shop on AmazonSmile

amazonsmile

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Questions: Contact donate@lgdalliance.org

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