

Lymphangiomatosis & Gorham's Disease Alliance

INTERNATIONAL FUNDRAISING TOOLKIT

1. GETTING STARTED

Why become a volunteer?

We choose to fundraise for LGDA because of its focus on giving support, knowledge hope to us as patients and our families.

How to become a volunteer?

1.	2.	3.
Choose your fundraiser	Donate & raise money	Share your story

2. GET TO KNOW LGDA

What we do?

The Lymphangiomatosis and Gorham's Disease Alliance (LGDA) and sister organization LGDA Europe:

- Raise awareness
- Provide information on lymphangiomatosis and Gorham's disease.
- Offer support and hope to patients and their families
- Enable contact between patients
- Connect patients to doctors and clinical centers and vice versa
- Work with other health organisations
- Promote research

Know the facts

- 252 patients are registered worldwide with lymphangiomatosis and Gorham's disease.
- Males and females are affected equally.
- All races are affected equally..
- It is not a hereditary disease.
- In the 20th week of a pregnancy congenital errors occur causing this disease.
- 68% of patients have bone involvement.
- Lymphangiomatosis is a rare lymphatic disease.

- 75% of patients with lymphangiomatosis have involvement in multiple organs.
- Gorham's disease is a rare bone disease.
- Gorham's is also known as vanishing bone disease.

3. CHOOSE YOUR FUNDRAISER

Host an event

See our [A-Z fundraising activities](#).

Become a brand ambassador

- T-shirts
- Craft items
- Posters
- Banners
- Pens
- Etc.

Create an online fundraiser

- Bake sales
- Craft sales
- Donate your birthday
- Dye your hair
- Sports challenges
- Etc.

4. BEFORE YOUR FUNDRAISER

5 things to do before your fundraiser:

1. Choose your time.
In this case May 26th! But you can always choose another time.
2. Set a goal.
3. Choose a name.
In this case LGDAwareness Day! But you can always organise another fundraiser with another name.
4. Approve all materials (logo etc.)
5. Prepare all the necessary paper work.

5. DURING YOUR FUNDRAISER

5 things to do during your fundraiser:

1. Be the first to donate.
Inspire others by making the first donation yourself. Make your donation the same amount you hope for your supporters to contribute. Encourage others to match this donation.
2. Share.
Get the word out on social media, email and personal phone calls. Ask your friends to help promote your event and invite everyone to join. Flyers, posters, Facebook posts and tweets can help inform a wide audience in a very short amount of time. Tag @LGDAlliance on social media so we can see what you are doing, and celebrate with you.
3. Ask!
Don't feel guilty about asking. Lots of people plan on donating, but simply forget due to your email getting buried in their inbox – follow up and encourage them to donate early.
4. Document your event.
Take pictures, video survivor stories and get quotes from participants and donors. Don't forget to send these to us as well!
5. Be transparent.
If you are donating a percentage to the LGDA, make sure your audience knows your intentions.

SOCIAL MEDIA GUIDE

DO'S	DON'TS
Use the Share-button on the fundraising page	Make duplicate posts on multiple walls
Tag LGDA (Europe) in your posts	Send @ replies with duplicate content
Use the hashtag #LGDAAwareness	Post suggestive images
Tag your friends who have donated, to say thanks	Make every post an ask. Share inspiring and positive anecdotes as well.

Facebook

We have created a Facebook Event: World LGDA Awareness Day.

- Invite people to attend.
- Share this event.
- Share your story.
- Thank donors by giving them a Like.
- Tag LGDA (Europe).

Twitter

- Introduce your fundraiser to your followers: briefly explain why you are #LGDAwareness.
- Share a link to your fundraising page or a website where they can learn more.
- Tweet before, during and after your fundraiser.

Instagram

- Take photos of your fundraiser.

Share by email

- You can reach multiple people quickly and effectively.
- Write why you are fundraising, what you are doing to fundraise and how to donate.

6. AFTER YOUR FUNDRAISER

3 things to do after your fundraiser:

1. Submit your donations (links below).
A standard rule is to submit donations within 30 days.
2. Follow-up.
No matter how big or small your fundraiser is, it's important to let people know about your success. Consider including some inspiring stories, send a thank you note, encourage others to create their own fundraisers.
3. Start planning for next year.
Look what you did right and wrong, learn from every perspective of your planning and execution. It's never too early to start planning for next year's event!

SUBMIT DONATIONS

[LGDA US](#)

[Alfie Milne Trust](#)

[LGDA Belgium](#)

[LGDA Nederland](#)

QUESTIONS?

United States: info@lgdalliance.org
Europe: info@lgdalliance-europe.org
United Kingdom: info@alfiemilne.org