

**1) Board of Trustees**

Due to COVID 19 no face to face Board meetings have taken place. As and when a charity matter emerged requiring a Board decision the matter was discussed and voted on by email.

**2) Networking**

**a) Lymphangiomatosis and Gorham's Disease Alliance (LGDA)**

LGDA-UK continues to have close ties with the United States-based Lymphangiomatosis and Gorham's Disease Alliance (LGDA). In April 2020, Tracy took on a paid two-year contract as the LGDA's Assistant of Patient Programs. As a paid contractor Tracy had to resign from the LGDA Board.

**b) Lymphangiomatosis and Gorham's Disease Alliance – Europe (LGDA-E)**

In addition to the US LGDA involvement, Tracy attends the LGDA-Europe representing LGDA-UK, with monthly virtual meetings and shared projects. Focus has been on upgrading the LGDA Europe website to reflect changes in disease information and to give the user a better experience when visiting the website. As a national charity the LGDA UK now has its own page on the website and can receive direct donations through Paypal or Virgin Money Giving.

The organisation is also working with the company Salesforce on a bespoke database to help manage our community of patients, families and supporters across the UK and Europe. This database will be used to record all UK patient and family contacts.

In addition to the database construction, the LGDA-e website requires an overhaul. This work is being undertaken by a Dutch company – Lubach.

Upgrading the website and building a database are two sizeable and it was agreed by the national charities that they warranted a dedicated paid person to oversee all the project work and act as liaison between the LGDA Europe, Lubach and Salesforce. The work is ongoing.

European Reference Networks (ERN) – The VASCERN is a formal network of doctors from across the European Union working to provide accessible cross-border healthcare to patients with rare vascular diseases. Following Brexit, the UK are no longer eligible to be part of the ERN. The LGDA UK will no longer be involved or benefit from the activities undertaken to help patients with complex lymphatic anomalies. . This is a massive loss, leaving the UK isolated from the collaborative work of EU doctors and researchers.

**c) Rare Disease Networking**

Rare Revolution Magazine - We have once again paid the annual subscription fee to this non-profit rare disease magazine. As a charity partner we get first refusal on submitting articles to be circulated through this global magazine. In the April 2021– Rare Bone Disorders edition we were able to share a patient story and also promote the LGDA's forthcoming virtual conference scheduled for October 2021.

**3) Patient Support**

**a. Building Patient Communities**

LGDA-UK continues to work with its global partners to connect and build patient communities.

**b. Individual Patient Support**

The charity handles e-mails and telephone calls from those looking for information on lymphangiomatosis and related conditions, and actively introduces our work to any new contacts received via GOSH, LGDA or other means. New patients continue to come forward for support. We have seen a total of 37 new members joining our community globally, of which, only 4 are from the UK.

**4) Research**

**a) LGDA Research**

In June 2020, £10,000 was awarded to the LGDA in the US by the LGDA UK to support the Million Dollar Bike Ride fundraiser. This is an annual event which usually takes place in Philadelphia but in 2020, due to the pandemic, it became virtual allowing more families to be involved globally. There were teams from the UK, Belgium and the US as well as a small number of families doing their own individual fundraising. In total, \$81,965 was raised which includes \$30,000 match funding by the Upenn Orphan Disease Center. These funds are dedicated to carefully-selected research projects, and this year, the award went to Andrea Del Fattore, PhD, to fund his project Understanding the effects of Sirolimus/Zolendronic acid treatment on bone remodeling activity in patients with Gorham-Stout disease. Dr. Del Fattore is the Head of Bone Physiopathology Laboratory at Bambino Gesù Children's Hospital in Rome.

**b) AllStripes Research Program**

In November 2020 the LGDA partnered with AllStripes, a medical data science company, to create a database that will enable multiple new Complex Lymphatic Anomalies (CLA) research projects. By signing up to the program patients give the AllStripes team permission to collect medical records – the goal is to compile clinical information from many patients for researchers to study patterns of symptoms and response to treatment in order to learn more about rare diseases. This campaign was firstly rolled out in the US and Canada and then became available in the UK in February 2021. The LGDA UK have been involved in recruiting patients globally. Recruitment is ongoing and to date we have 10 UK patients signed up to the program and a further 67 from US and Canada. This is a very exciting opportunity for our patients to get involved in and help advance research in to developing new drug therapies.

**5) Awareness**

**a) General Awareness Raising**

Lymphangiomatosis and Gorham's Disease Day took place on 26<sup>th</sup> May 2020. This awareness event is registered with Eurordis and offers a terrific opportunity to engage the patient community and raise public awareness of the conditions and the work of the organisation. A social media campaign ran on the day featuring patients sharing photos and telling their stories.



**b) Alfie's Trust Website**

The Alfie's Trust website will remain live with content about Alfie's journey, but the Homepage will direct viewers to an LGDA-UK section on the LGDA-E website. Work is ongoing on this, and when complete, updates will no longer be made to the Alfie's Trust site.

**5. Fundraising**

There is no charity-run fundraising activity to report. Due to COVID 19 this has been a difficult year for the charity with donations and fundraising activities at an all-time low. However, for the last 7 years the LGDA has taken part in the Million Dollar Bike Ride event to raise funds for research. Due to COVID, as mentioned in the LGDA research section of this report, the event became virtual and the LGDA UK were able to promote this to our UK and European community of supporters.

We received donations through two online fundraising events organised by supporters, and our passive fundraising, Easyfundraising and SmileAmazon, has seen a trickle of money coming in throughout the year. A total of £6,735.04 has been raised in this financial year.

No restricted funds have been used in this financial year, the total figure ringfenced for nominated uses by donors remains at £6,859.78.