

On October 18th, 2021 the board made the decision to wind down the LGDA UK charity. The LGDA UK will remain in name only and will be a support and information hub only for UK patients and parents of young children. The reporting year was extended from 31<sup>st</sup> March 2022 to 31<sup>st</sup> July 2022 to allow for distribution of funds. The bank account closed on at the end of June 2022 with a balance of £2069.35. The remaining amount was transferred to University College London to go towards the CLA research being carried out by Dr.Polubothu at Great Ormond Street Hospital.

## **1) 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). The LGDA UK will be the point of contact for UK patients and parents of young children affected by complex lymphatic anomalies, working with the LGDA to provide up-to-date information and access to a global community of patients and parents.

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

In addition to the US LGDA involvement, Tracy is now a Board member for LGDA Europe, attending monthly virtual meetings and shared projects. This includes sharing UK information and updates on the shared website and social media platforms.

To help with community messaging and engagement, in July 2021 the LGDA UK supported a grant of £887 to help with improvements to the LGDA website and the establishment of a CRM.

Following the decision to wind up the LGDA UK, the LGDA Europe was granted a further £43,000 for general use to enable the organisation to continue to support its mission.

## **2) 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 LGDA UK 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.

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### **3) Research grants**

#### **a. LGDA (USA)**

- June 2021 - the LGDA was awarded £13,000 to support the Million Dollar Bike Ride (MDBR). An annual event organized by the Penn Medicine Orphan Disease Center in Philadelphia. Together with our global partners a sum of \$82,000 was raised for CLA research.
- February 2022 - a further £50,000 was granted to support a Young Investigator's Research Program initiated by the LGDA.

#### **b. LGDA Europe**

- March 2022 - a £50,000 grant restricted for CLA research purposes. Each grant being restricted to CLA research.

#### **c. Great Ormond Street Hospital (GOSH)**

- April 2022 – An award of £50,000 was granted to Dr Polubothu, PhD, at Great Ormond Street Hospital to support a 2 year CLA research project on Genetic investigation and novel therapies in complex lymphatic anomaly
- June 2022 - £2069.35 CLA Research, Great Ormond Street Hospital

#### **d. Cincinnati Children's Hospital Medical Center**

- May 2022 - Cincinnati £2,000 awarded to support ongoing CLA research carried out by Dr Timothy D. Le Cras, PhD

### **4) General Awareness Raising**

Lymphangiomatosis and Gorham's Disease Day took place on 26th May. This 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.

### **5) Fundraising**

There is no charity-run fundraising activity to report. During the financial year we have received funds from a handful of UK patient families with the remaining funds coming in from passive fundraising (Easyfundraising and SmileAmazon), collection tins, gift aid and bank interest. A total of £6915.95 raised in this financial year.