

The Alfie Milne Lymphangiomatosis Trust was established in 2012 after Alfie was diagnosed with lymphangiomatosis. The charity has since been fundraising and developing patient and research networks, with Alfie in attendance as the face of the organisation. Alfie, now approaching his teenage years, has taken a step out of the limelight to focus on 'just being a teenager'.

As the Trust has developed, we are working more and more with our European and American partners in the Lymphangiomatosis and Gorham's Disease Alliance (LGDA). Working together makes us stronger and allows us to pool resources - sharing and coordinating the workload to benefit our worldwide community.

With these factors in mind, the Alfie's Trust Board agreed to change the charity name to align with our international partners, becoming the Lymphangiomatosis and Gorham's Disease Alliance-UK (LGDA-UK). This change was formalised and registered with OSCR in November 2019.

## **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). Our Chair, Tracy Milne, attends quarterly virtual meetings of 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.

### **c. Rare Disease Communities**

Tracy attended a workshop at Great Ormond Street Hospital in June 2019 to discuss the potential requirement for a British Society of Vascular Anomaly and Overgrowth. No further action has taken place on the formation of this society.

### **d. Medical Community**

LGDA-UK has acted as an intermediary, introducing researchers in the UK to doctors and researchers in Spain and Belgium to enable knowledge-sharing, as well as discussion on sharing of bone samples.

## **2. Patient Support**

### **a. Building Patient Communities**

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

### **b. Dr Lopez' Clinic, Madrid**

Dr Lopez has further developed the open review clinic in Madrid that was established last year, available to all European patients. This has been attended by a number of patients from a variety of countries, including the UK. A welcome letter is being prepared for patients attending the clinic, introducing them to the support of the LGDA-E. The aim is for patients to join the LGDA Patient Registry, and ultimately to form a Spanish arm of the LGDA-E.

**c. 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.

**3. Research**

**a. LGDA Research**

Alfie's Trust collaborated with the LGDA-E to contribute to LGDA (US) funding for research via the Million Dollar Bike Ride fundraiser at the University of Pennsylvania. Funds raised at this event have allowed the commencement of a \$63,000 research project seeking to develop a model with which to test the repurposing of antiangiogenic drugs in treating lymphatic malformations.

**b. Rudy Study**

The Rudy Study is the first UK rare bone disease study, which is now open to all rare diseases. Patients with lymphangiomatosis and Gorham's Disease were invited by Alfie's Trust (now LGDA-UK) to take part in this online-based study tracking symptoms and collating data on the conditions. Twenty patients are required to participate, 7 have registered to date. This figure has remained the same for a year, and no further action will be taken to recruit patients at this time.

**c. Consolidation of Lymphatic Anomalies Program (Research Assistant - Dr Triana, Madrid)**

In collaboration with the LGDA and LGDA-E, the LGDA-UK has funded a research assistant post working with Dr Lopez in Madrid. Dr Triana has been in post since September 2018, working on a range of topics around the consolidation and expansion of the lymphatic anomalies program underway at La Paz Children's Hospital. These involve working with a multidisciplinary team and cover protocol improvements and development, registry updates and network expansion. This is a two-year program, with funding for 2019-20 awarded following release of the initial report in September 2019.

**4. Awareness**

**a. General Awareness Raising**

Lymphangiomatosis and Gorham's Disease Day took place on 26<sup>th</sup> May. This is registered with Eurordis and offers a terrific opportunity to engage the patient community and raise public awareness of the conditions. 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**

A decision was taken by the charity Board of Trustees to suspend all major fundraising efforts and events. As a result, there is no charity-run fundraising activity to report. However, supporters are continuing to donate and fundraise for the charity, with an income of £10,019 coming from:

- miscellaneous donations totalling £7,585



- individual donations
- collection tins
- passive fundraising like Easyfundraising, Ebay and Amazon Smile
- bank interest earned, and
- Gift Aid
- A further £2,434 donated as a result of events by supporters
  - BHGE 10
  - Inverness to Aberdeen Cycle
  - Ultramarathons
  - Race to the Stones, and
  - cycling events run by the Westhill Bike Club.

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

#### **6. Board of Trustees**

Myra Leiper, who has been Treasurer of the charity since its inception has retired this year. She will be missed, the role will be covered by Tracy Milne.