

The fiscal year 2016-17 has been one of consolidation for Alfie's Trust. The new Board of Trustees have helped to establish structure and realistic targets, enabling work to continue on strengthening links with other patient organisations.

This report outlines activities and achievements for the year 1st April 2016 to 31st March 2017.

1. Networking

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

Alfie's Trust 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.

A grant of \$15,000 was made to the LGDA. Initially intended to part-fund a medical conference in June 2016, it was agreed that this sum should be diverted into a fundraising pool for research projects.

Alfie's Trust, the LGDA and LGDA-E are continuing efforts to improve information-sharing, particularly with reference to contact information for patients, doctors, researchers and supporters.

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

In addition to the US LGDA involvement, Tracy also chairs the LGDA-Europe with bi-monthly virtual meetings. In May 2016, Tracy represented Alfie's Trust and the LGDA-E at a Eurordis Conference, the theme of which was the European Reference Network – a scheme which will allow cross-border treatment of rare diseases.

A Patient and Family Conference was held by the LGDA-E in The Netherlands in November 2016. This was part-funded by Alfie's Trust, who offered grants for accommodation to attending families. The conference took place over three days and included talks by doctors, including the LGDA-E's Medical Adviser, Dr Roessler from Freiburg, as well as offering the opportunity for patients to meet and volunteers to form work groups on assorted topics to be taken forward after the conference.

c. Supergroup

In 2015, through the main research contact at Great Ormond Street Hospital (GOSH), Dr Veronica Kinsler, Alfie's Trust was introduced to a group of patient organisations whose conditions are also the subject of research at GOSH. Despite high hopes for valuable interaction with this group, it has not happened. A volunteer co-ordinator was appointed by Dr Kinsler in July 2016, but has not progressed the group.

d. British Association of Dermatologists (BAD)

Alfie's Trust became members of this body, and were represented by Tracy who took a stand at the BAD Annual Conference in July 2016. Few of the conference delegates showed an interest in the information on offer from patient organisations, but it proved an excellent opportunity to network with other patient representatives.

e. Rare Disease Communities

An Open Day held at Great Ormond Street Hospital in June 2016 brought together patients' families and representatives of patient organisations. Four families affected by lymphangiomatosis attended.

On Rare Disease Day in February 2017, Tracy represented Alfie's Trust at an event held by NHS Grampian, and was introduced to two new local contacts with rare diseases. In March 2017, Tracy was introduced to the head of Me Too! – an organisation aiming to enable inclusive activities for disabled children and their families. These contacts will be maintained to build on the local rare disease community.

2. Patient Support

a. Lymphangiomatosis Facebook Groups

Alfie's Trust continues to work with the LGDA to administrate, monitor and participate in Facebook support groups. There are two groups with a combined membership of almost 300 - a Patient Group (patients and parents only) and a Friends and Family group. These remain active communities.

b. Ad-hoc Enquiries

The charity also handles e-mails and telephone calls from those looking for information on lymphangiomatosis, and actively introduces ourselves to any new contacts received via GOSH, LGDA or other means.

c. Family Day

Consideration was given to hosting a Family Day in the UK – a mainly social occasion for patients and their families to meet. This idea was parked in the event of both the GOSH Open Day and the LGDA-E Family conference taking place, but may be reconsidered in the future.

3. Research

a. Great Ormond Street Hospital (GOSH) Genetic Research

Part-funded by Alfie's Trust in June 2014 and led by Dr Veronica Kinsler, a genetic research project at Great Ormond Street Hospital continues. This was expected to be a two-year project but is ongoing with the aid of a research assistant. A further funding application is likely in 2017, with details expected on further development of the project.

b. LGDA Research

The LGDA in the US have their own research programme. A \$15,000 donation was granted by Alfie's Trust in 2016 towards a funding target of \$50,000. This target will be matched by the University of Pennsylvania and will fund research into lymphangiomatosis and Gorham's Disease. Details of specific research projects are yet to be confirmed.

c. Rudy Study

Details have emerged on the first UK rare bone disease study – The Rudy Study. Patients with lymphangiomatosis and Gorham's Disease have been invited by Alfie's Trust to take part. It is an online-based study which will track symptoms and collate data on the conditions.

4. Awareness

a. GOSH Leaflet

In 2015-16, Alfie's Trust worked with GOSH to prepare an information leaflet about General Lymphatic Anomalies, of which lymphangiomatosis is one condition. This has now been published online, and was distributed in hardcopy along with an insert about Alfie's Trust at a GP conference in October 2016, thanks to a contact made at the BAD conference.

b. Alfie's Trust and LGDA-E Websites

Both websites have been relaunched this year, with many thanks to all who worked on them – especially Tracy Ridge and Engage PR on the Alfie's Trust site. The LGDA-E site has been translated into a few different languages, and further translation will continue to help reach non-English speaking patients.

c. General Awareness Raising

As always, Alfie's Trust maintains a presence in local community press, and with our Alfie's Trust T-shirts and fundraising efforts at various local events throughout the year – see below.

Thanks to her attendance at the BAD Conference, Tracy was offered the chance to write an article which was published in the March 2017 edition of *Dermatological Nursing: The Journal of the British Dermatological Nursing Group*.

2017 will see the inaugural global Lymphangiomatosis and Gorham's Disease Day on 26th May. This day is registered with Eurordis and offers a terrific opportunity to raise awareness of the conditions.

5. Fundraising

Almost £32,000 has been given to the Trust in this financial year, the Financial Report contains full details of funds received during the year. We are delighted with this total, having exceeded our stated fundraising target of £20,000 by 60%. As in previous years, we had teams taking part in Run Balmoral and the Kiltwalk, but we had no corporate sponsorship in 2015-16, so all funds raised at these events were entirely down to our supporters.

Our new Fundraising Co-ordinator, Stewart Gardiner, must be acknowledged for his role in maximising funds received, particularly for the events he managed – a Night at the Oscars and a Curry Night. Other successful fundraising events were Golf, the annual Craft and Tea Afternoon and an online Christmas Campaign.

It should be noted that approximately £2,831 of funds received have been accepted with the understanding that they are to be restricted for use by the LGDA-E.